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**TRANSITIONS IN THE LIVES OF ADULTS WITH
SEVERE INTELLECTUAL DISABILITY: AN
ECOLOGICAL LIFE COURSE PERSPECTIVE**

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**Thesis presented in fulfilment of the requirement of the degree of
Doctor of Philosophy**

THE UNIVERSITY OF EDINBURGH 2020

Declaration

I hereby declare that this thesis has been composed by me and is entirely my own work. The work presented in this thesis has not been submitted for any other degree of professional qualification.

Paula Charlotta Jacobs

Acknowledgments

I need to thank a number of people who have supported me along the way. First and foremost, I would like to thank my supervisors: Ken MacMahon, Ethel Quayle and Heather Wilkinson for all their encouragement, advice and interest in my research. I also need to express my gratitude to the people who took part in this research and were so generous to share their time and stories with me. Lastly, I thank friends and family who listened to my ideas and thoughts. Particularly, Scott who pushed me through the last stretch and my sister Lina who read the whole thesis once.

Those are the people I would like to thank. There are also a number of people I would like to dedicate this thesis to. I would like to dedicate my thesis to the young people I met when I first came to Scotland to volunteer at a residential community. I came with the plan to stay for one year but never managed to leave again. Meeting you all has been a great inspiration to me and truly changed my life. Rebecca, Emma, Beth and Dominik, I hope you are well and happy. I often think of you. And of course, Jon. I am very grateful that I am still able to be part of your life.

Abstract

Change is part of our life journey and we all experience different transitions throughout our lives. However, people with intellectual disabilities often experience a lack of control and involvement in transition planning and transition processes. Within the current literature there is a focus on early transition experiences, such as people's school years, while adulthood remains a lesser researched chapter in the lives of people with intellectual disabilities. Furthermore, most studies focus on those with mild or moderate intellectual disability and people with severe or profound intellectual disabilities are often excluded from research. In relation to those with severe or profound intellectual disability, transition processes pose questions about decision-making capacity and how to facilitate involvement and participation.

A systematic review of the transition from school to adult services for young people with severe intellectual disabilities highlighted the importance of a life-course understanding to transitions, as well as highlighting gaps in relation to (1) the absence of multiple perspectives, even though transition processes involve multiagency decision-making, (2) a lack of involvement of young people and adults themselves within the research process and (3) a lack of focus on transitions as processes that operate across different ecological levels. Building on the identified gaps this thesis presents three interlinked studies that explore transitions across people's adult lives. Namely, (1) the transition from school to adult services, (2) transitions within adult services such as moving out of the family home and (3) transitions in old age. Qualitative case study methodology was used in combination with approaches from ethnography, life story research and framework analysis. The first two studies followed six adults on their transition journeys and data collection involved observations, document reviews and interviews with families and professionals involved in each case. One of the main aims of my PhD was to involve people with severe intellectual disabilities in the research process and it was hoped that through the use of different data sources young people and adults would be more present in the research process compared to previous studies. The third study explored transitions in old age through interviews with social care professionals in two distinct social care settings, where adults with intellectual disability and staff lived together within a life-sharing model.

The findings of my PhD confirm the value of a life course perspective and demonstrate that transitions are complex processes that occur across, and are influenced by, different systems. Additionally, my findings emphasise the importance to consider relationships and support networks that are available to people with severe intellectual disability within their adult lives when planning and supporting transitions. Questions are raised in relation to the role of professionals and services in the lives of adults, particularly once parents are no longer able to advocate on behalf of their children. Furthermore, the need to reconceptualise participation from a relational and interdependent perspective is stressed to facilitate the involvement of people with severe intellectual disabilities within decision-making processes. Further research is needed that explores the everyday life experiences of this particular group and that includes people within the research process.

Lay summary

People with severe and profound intellectual disabilities need others to support them in most areas of their life from childhood to old age. It can be difficult to communicate with people about change and transitions have been identified as an area of concern, particularly how to involve the person in decisions that are made and to ensure that decisions keep the person's best interest in mind. My PhD looked at different transitions in the lives of adults with severe and profound intellectual disabilities. The transitions I explored were:

1. Transitions from school into adult services
2. Transitions out of the family home and into supported accommodation
3. Transitions in old age

For my research I met six adults with severe and profound intellectual disabilities who were at different life stages in their adult lives. I spent time with them and talked to their parents, social workers, teachers, social care staff, health professionals and local authority managers about their transitions and how they were involved in decisions that were made. I also spend time at two adult services to speak to their staff and find out how they support people with intellectual disability during transitions in old age. Speaking with everyone involved reflected the complexity of understanding what adulthood means for people who will continue to need support throughout the course

of their lives. While the practical aspects of transitions were described as positive, barriers and limitations were identified in the wider organisational context and available resources, policies and cultural beliefs influenced decisions that were made.

Overall, my PhD shows the importance of relationships between people. Relationships people had to family members and key-staff facilitated their engagement and experiences of the world. Therefore, it is important that those who know the person well are closely involved in the planning of transitions. Additionally, there should be a greater focus on maintaining and broadening the relationships that people have so that we can build bridges between settings and places.

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1. INTRODUCTION

I worked within the practice field of Intellectual Disabilities (ID) in Scotland for nine years prior to starting my PhD. I came to Scotland in 2007 to work at a therapeutic community and residential school for children and young people with additional support needs and although I had only planned to stay for one year I ended up staying for seven. The community was one of several Camphill communities in Scotland. Camphill communities are based on a life sharing model and during my time at the school I lived together with around seven children and young people with additional support needs and other staff, sharing living spaces and meals. I mainly supported young people with severe or profound ID and becoming a part of their lives and that of their families greatly touched me. My work challenged views and beliefs that I had previously taken for granted. Although the young people I worked with used very little verbal communication and depended on others to a large extent, I did not experience our relationships as one-sided. Contrariwise, I gained great personal value from the relationships I formed with the young people and I learned to find different ways to communicate with and relate to them based on their unique ways of expressing themselves. I continued to work in learning disability services in Scotland while completing my under- and postgraduate degrees part-time and so most of my university essays and my MSc dissertation focussed on the area of severe ID. When I spoke to other students about my work or research interest, I often encountered questions such as: 'What do you mean they are non-verbal? They will always need support? Where do they live and what do they do all day?' I was surprised how many people seemed unaware that people with severe ID exist and had never met a person with complex support needs. I was reminded how the lives of people with severe ID, and that of their families, seem to be hidden from many areas of society.

I became interested to explore transitions through my work. Many transitions of the young people I supported did not go smoothly and many families were anxious about their children leaving the school. My MSc project further focused my interest on the transition to adulthood (Jacobs and MacMahon, 2016). For my MSc dissertation I interviewed young adults with siblings with severe ID in residential care. Coincidentally, participants and their brothers and sisters all spanned the age range of emergent adulthood. In the interviews participants talked about becoming aware

that their own pathways and that of their siblings had started to differ significantly. As participants talked about living away from home, starting their own lives and careers, they expressed a wish for more networks for their siblings outside the family. They felt that while their own worlds were widening, their sibling was in danger of losing important networks through the ending of school. This image, of the reverse movement of a world closing down, stayed with me and I decided to explore transitions to adulthood further in my PhD.

1.1 People with severe intellectual disabilities – Lost voices?

It is not that long ago that people with ID were largely excluded and hidden from mainstream society and placed in institutional care across the western world. This started to change in the 70s with a move towards social and educational inclusion and disability rights. People with severe ID were often the last ones to leave institutions and they continue to be more likely to be placed in out-of-area placements and residential care facilities (Mental Welfare Commission, 2016b, MacDonald, 2018). Furthermore, while educational and social inclusion have been adopted as a policy target by most western countries, many children with severe ID are still educated in special educational settings (Colley, 2020, Lacey and Scull, 2015). The research reports a lack of meaningful activities for people with severe ID in adulthood (Gauthier-Boudreault et al., 2019) and the family and care and education services are often their main, and at times, only social networks (Kamstra et al., 2015, Mietola and Vehmas, 2019, Wilder, 2008). Similarly, while there has been a new policy focus on supporting access to employment and independent living for people with ID (Scottish Government, 2013, Scottish Government, 2019) the meaning of concepts such as self-determination or independence for adults with severe ID has been called into question (Kittay, 2001, Rogers, 2016).

The ‘invisibility’ of people with severe ID in society is mirrored within the research community, which has largely neglected them as a group (Klotz, 2004). The reasons for this include ethical concerns in regard to power-imbalances, consent and vulnerability, alongside the complexity of involving individuals with profound communication difficulties. However, a new body of research literature is exploring the possibilities of including individuals with severe ID within research (Mietola et al., 2017,

Nind, 2008, Simmons and Watson, 2014, Ware, 2004). I believe that while it is important to be aware of ethical concerns, the exclusion of people with severe ID from research can further contribute to their marginalization, because it leads to a lack of understanding of what their lives are like and a lack of knowledge of their specific needs (Klotz, 2004, Ledger, 2012).

1.2 Why focus on transitions? – a holistic approach

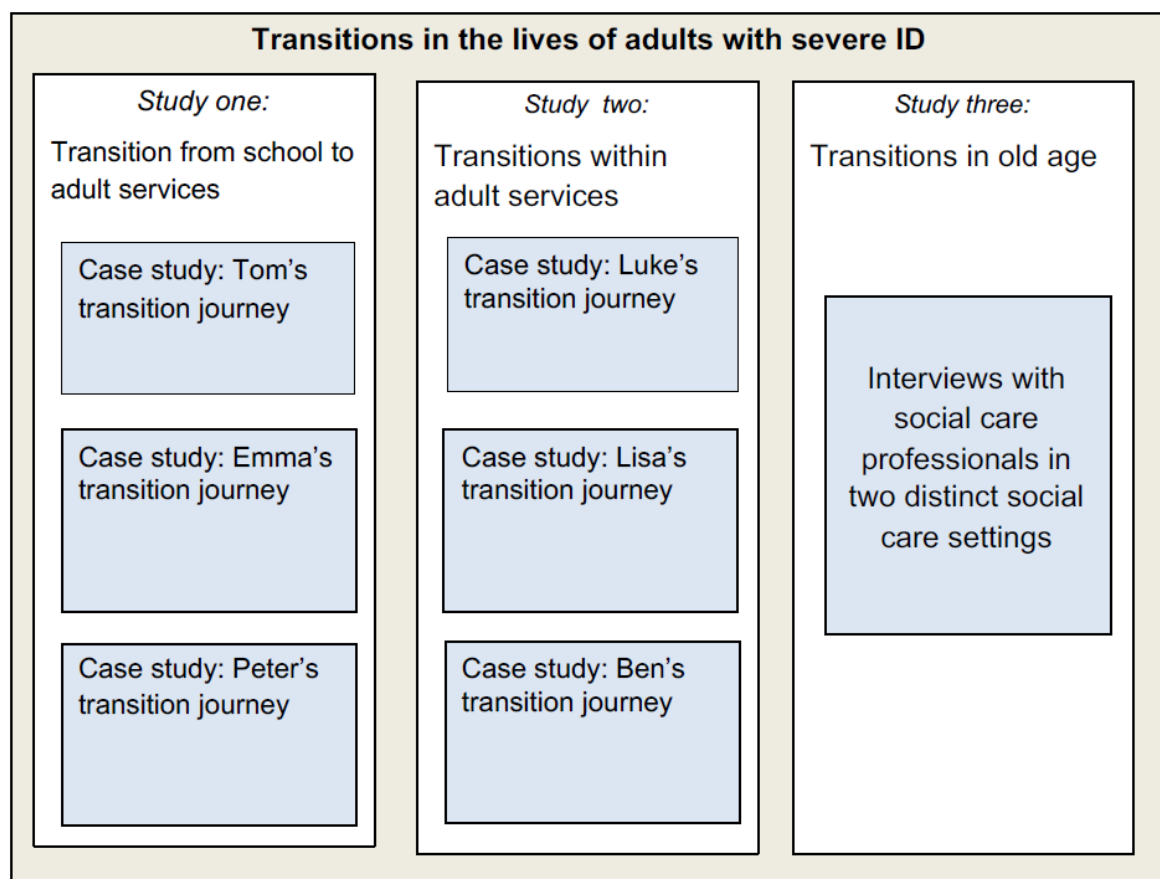
Research and policy reviews that examine the lives of individuals with ID have identified transitions as a critical topic that requires attention (Scottish Government, 2013, Jindal-Snape, 2016). People with ID will experience numerous changes and transitions across their lives, just like all of us, but the difference is that people with ID often have little involvement in the decisions being made. Local government provides many of the services used by individuals with ID, their families and carers, and a wide range of professionals are involved in delivering services. Thus, changes experienced by people and their families are largely shaped by bureaucratic processes and decisions made by professionals (Hardy et al., 2005, Murray, 2006) and transitions are often conceptualized as changes within service delivery, instead of developmental processes (Redgrove et al., 2016). Within the standing literature on transitions few studies define what they mean by transitions and in those that do, transitions are often conceptualized as a physical move between services (Jindal-Snape et al., 2019b), which emphasizes a view of transitions as one-off events (Cox, 2017, Jindal-Snape, 2016). Yet, research shows that individuals often need many years to adapt to transitions and that transitions are complex processes that include small changes and adjustments before, during and after the 'big' change (Jindal-Snape, 2016). Recently, the concept of multidimensional transitions has started to gather recognition within transition research (Jindal-Snape, 2016, Jindal-Snape et al., 2019a). The concept describes how transitions are influenced by people's immediate environments, as well as organizational practices and the wider socio-economic context. Furthermore, the concept highlights that transitions never only happen to one person. Instead others within the person's immediate environment will be influenced by the change as well and will simultaneously influence the process (Jindal-Snape, 2016, Jindal-Snape et al., 2019a). For example, research has shown how a decrease in respite for families in adult services often influences the abilities of mothers to continue to work (Hubert,

1991, Murray, 2006) and so mothers will go through their own change in life circumstances. Accordingly, this study aims to take a multidimensional perspective to transitions, to capture that transitions are processes, not events, and that they involve networks of people and take place on different levels.

1.3 Overview of the research process

My PhD started out with a focus on the transition from school to adult services but it later developed into a more organic design where the findings from three consecutive stages fed into each other in order to explore further transitions in adulthood, namely transitions within adult services such as moving out of the family home and transitions in old age. An overview of the three studies can be seen in the table below.

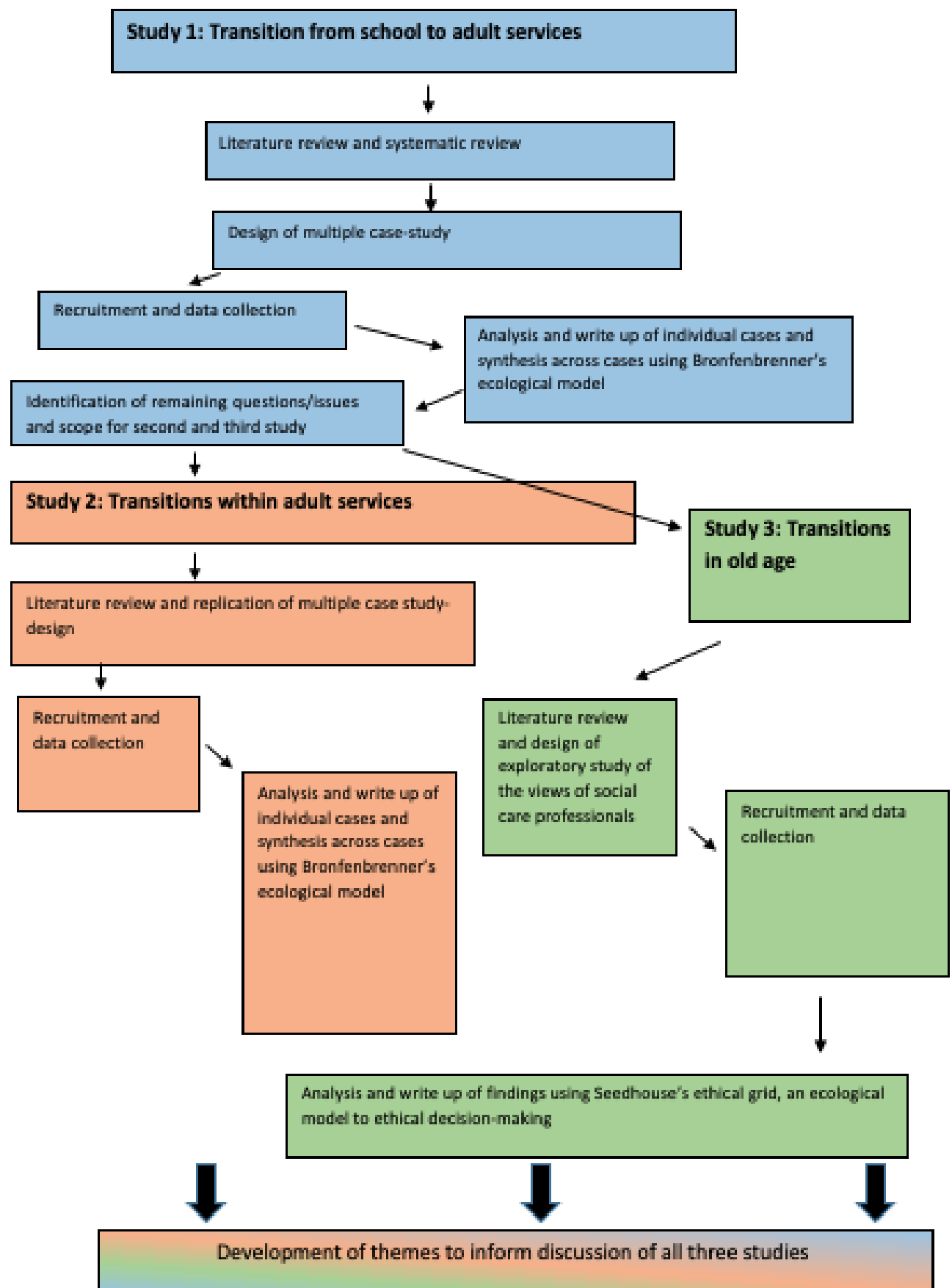
Table 1: Overview of three studies



One of the main findings of my first study that explored the transition from school to adult services, was a recognition that it was unhelpful to conceptualise transitions as one-off events. Once young people had moved to adult services a lot of questions remained for participants in the first study and they anticipated further changes within adult services such as young people moving out of the family home or changing service providers. Additionally, participants seemed unsure how to conceptualise adulthood and wondered how the adult lives of the young people would look like. This led me to design a second study that mirrored the design of the first, but focused on transitions within adult services, and to conduct a third study to explore transitions in old age to reflect further on the fundamental question parents kept repeating in interviews in both study one and two: 'What will happen when we are no longer here?' Existing studies on the transition from school to adult services for people with ID have emphasised that transitions should be understood within people's whole life journeys (Hubert, 1991, Cox, 2017), but few follow transitions past the point of leaving school. I was interested to explore the continuity of change across people's adult lives and to explore similarities and differences in people's experiences of transitions and changes in adulthood.

The flowchart below (Figure 1) illustrates how my focus moved from the transition from school to adult services, including a systematic review, to include further transitions across people's adult lives. Study one and two were based on a multiple-case study design, while study three was an initial exploration of transitions in old age utilising interviews with social care professionals only.

Figure 1: Overview of research process



1.4 Aims of research

My research developed out of an awareness of the absence and invisibility of the lives of people with severe and profound ID within the standing literature on transitions. Thus, my research aims to contribute to an understanding of how transitions are like for this particular group. This involves focussing on the question of how adults with severe and profound ID are involved in transition planning, as well as trying to find a way to include them and make their lives visible within the process of my research. It is after all their lives that are changed and them who should be at the centre. My aim is not 'to give voice' to the person with severe ID. I believe that people with severe and profound ID do communicate their feelings, likes and preferences and I agree with Rogers (2016) and Mietola et al. (2017) that the central questions should instead be in how far they are seen and listened to.

My thesis views transitions as complex, multidimensional processes that are inherently linked to people's past and future, that include a variety of stakeholders and that operate across different levels and systems. By drawing on multiple perspectives I hope to understand how professionals and families work together to support transitions and what influences their actions during the process. Additionally, by including the perspectives of family members and professionals I aim to examine support networks and relationships in the lives of adults with severe and profound ID and to identify spaces where they experience inclusion and participation and to locate spaces and practices that exclude them. This will include an examination of people's immediate environments, as well as examining in how far there is room for inclusion within the wider community, organisational practices and political and cultural spheres.

1.5 Theoretical framework: an ecological life-course perspective

While some researchers argue for the importance to come to the research process without pre-conceived ideas, I agree with Miles and Huberman (1994) who argue that it is impossible not to have some idea of what one is looking for. Instead of being a limitation, having a conceptual framework can help to focus and strengthen studies. It helps the researcher to know which areas are worth to explore and it helps researchers that work with complex data and multiple data sources not to lose focus among data overload (Miles and Huberman, 1994). While an ecological perspective informed my

study from the outset, the choice to take a life-course perspective alongside it, was taken after my systematic review of the literature and during the preliminary phase of data collection and analysis during study one.

1.5.1 Using an ecological framework

An increasing number of researchers and practitioners have moved towards a holistic and ecological understanding of disability to address its complexity across different levels (Davis et al., 2014, Jindal-Snape, 2016, Shakespeare, 2013). Additionally, ecological models have been used successfully in past research on transitions, including transitions within the school system (Jindal-Snape et al., 2019b, Ravenscroft et al., 2017), transitions in old age (Hardy et al, 2005), health care transitions (Jindal-Snape et al., 2019a) and transitions from school to adult services (Foley et al., 2012, Small et al., 2013). Small et al (2013) found that utilising Bronfenbrenner's (1979) ecological model in their research on the transition from school to adult services for young people with ID allowed them to identify barriers across different levels and to highlight interactions between levels. Similarly, Davis et al (2014) in their study on inclusive education and supporting transitions within education settings conceptualized transitions as holistic processes that simultaneously involve the person's family, educational, psychological, social and cultural spheres. An ecological focus is consistent with conceptualisations of disability within the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) and the Conventions of the Rights of People with Disabilities (CRPD) (United Nations, 2006). Both the ICF and CRPD use an ecological perspective to conceptualise disability as a dynamic interaction between the individual and his or her environment. Furthermore, the CRPD calls for an active involvement of all persons with disabilities in decisions that affect them, which illustrates a shift that stresses participation across ecological levels, not solely in relation to people's immediate environment, including involvement in policy-making and service provision (Löve et al., 2017, Mittler, 2015).

Ecological frameworks capture how change happen in an interdependent and relational manner. They require the researcher to have a double vision: (1) identifying the dynamic relationship between the individual and his/her immediate environment and (2) how this relationship is shaped by peripheral systems and forces. Therefore,

they allow researchers to capture the complexity of processes (Onwuegbuzie et al., 2013, Yin, 2003). In relation to people with severe ID multiple stakeholders and levels are involved within transition processes. Decisions are made between statutory services and families, and policies and resources available in local areas play crucial roles (Hardy et al., 2005). It was hoped that using an ecological framework for both data collection and analysis throughout my thesis would help get a deeper understanding of intersections between culture, policy, economy, organizational practices, local resources and the experiences of those affected (Olivier-Pijpers et al., 2020).

1.5.2 Taking a life-course perspective – dependency across the life-course

A life-course perspective highlights that transitions are journeys, which link to people's past and future. It allows researchers to connect one transition to previous and subsequent changes in the lives of people and therefore helps to understand transitions as processes instead of one-off events (Jindal-Snape, 2016). It has been suggested that a life-course perspective might be particularly beneficial to understand the experiences of people with ID (Cox, 2017, Ledger, 2012). The lives of people with ID are shaped early on by societal attitudes and bureaucratic practices and those continue to have a high influence on the lives of people and their families till the end. I believe that taking a life course perspective and attempting to capture the life stories and journeys of people with ID throughout their adult lives can help researchers to re-focus attention to the experiences of people who will often experience little power in decisions that affect their life (Chapman et al., 2006, Hreinsdóttir et al., 2006).

1.6 A word about terminology

Terminology on how to refer to people with ID has varied through history, reflecting cultural understandings and attitudes towards people with ID. This has included terms such as 'mental deficiency', 'idiocy' or 'feeble mindedness', which were used during the beginning and middle of the 20th century, followed by the term 'mental retardation', which was commonly used till the beginning of the 21st century. The American Association on Mental Retardation changed their name to the Association on Intellectual and Developmental Disabilities in 2007 (Nash et al., 2012). 'Intellectual disability' is now widely used as a term within both the fields of practice and academia

(Braaten, 2018, Schalock et al., 2007). I believe that particularly in relation to people with severe cognitive impairments the term 'intellectual disability' is more appropriate than terms such as 'learning disability' or 'learning difficulties'. The use of the word 'learning' might imply that difficulties only relate to people's engagement with education or their '*willingness to learn*' (Vehmas, 2010, p. 264), which does not reflect the wide-ranging limitations experienced by people across domains in their lives (Vehmas, 2010). Throughout the thesis I will use the term severe ID to refer to people with severe and profound ID. However, I am aware that terms create labels and I want to stress that I believe in the importance of understanding that people are more than a diagnosis. When discussing the cases of the young people and adults involved in this study, I will use their names (pseudonyms) or refer to 'young people' or 'adults' as much as possible without adding the label of 'severe ID'. Similarly, when referring to behaviour that is described as challenging by participants or the literature, I will use the term 'challenging behaviour', but I want to stress that I believe that challenging behaviour is a form of communication and a response to something that is causing the person distress.

Additionally, I need to clarify my use of the term 'adult service'. Throughout my thesis I will examine and discuss practices of both social work and social care professionals and services. The term 'adult service' will be used only to refer to adult social care services, including day services and supported living services. When referring to adult social work services I will explicitly use the term 'social work'.

2. LITERATURE REVIEW

This is the first of two chapters that focus on literature and publications. The latter chapter is a systematic review which provides a detailed account of what is known about transitions from school to adult services for young people with severe ID. In this chapter I present a more contextual approach to knowledge and research and I cover a diverse range of research areas to set the background to my topic. Thus, within my two literature chapters I move from a broader overview towards a more specific understanding of my research topic. I start this chapter by providing a definition of severe ID to try and achieve a common understanding. Secondly, I embed my research within its historic background by examining the move from institutional care towards community living for people with ID in the UK. Thirdly, I examine present social care practices and I explore what is known about the quality of life people experience and the quality of care they receive. Fourthly, I look at old age as a life stage that has only relatively recently started to be studied by researchers within the field of ID (Grant et al., 2001, Redley, 2019). Finally, the chapter ends with an outline of relevant policies and legislations.

2.1 Defining severe ID

During my reading of the literature it became apparent that authors often give different meanings to the terms severe or profound ID. Often, studies include participants with the ability to express their views, to live independently or be employed while using the terms severe or profound disability. Variations in terms used can result in uncertainty of who has been included in research. This is problematic as often findings are applied across the population of people with ID, even though the majority of research involves people with mild or moderate ID and many recommendations and conclusions will not be relevant to the lives of people with severe ID (Foley et al., 2012, Klotz, 2004).

2.1.1 Definition

The three main diagnostic frameworks (Diagnostic and Statistical Manual of Mental Disorders - DSM-5 (APA, 2013); International Classification of Diseases - ICD-11 (WHO, 2018); American Association on Intellectual and Developmental Disabilities (AAID, 2010)) use the following core criteria to define Intellectual Disability:

1. Deficits in intellectual functioning

2. Deficits in social and adaptive functioning
3. With an onset during childhood

Deficits in intellectual functioning have historically been based on IQ levels and grouped within four categories, which we now know as mild (under 70 to 50), moderate (35 to 49), severe (20 to 34) and profound (less than 20). However, the accuracy of diagnosis merely on IQ functioning continues to be contested, especially on the lower end of the spectrum (Whitaker, 2008). Therefore, diagnostic frameworks have moved to pay greater attention to adaptive functioning and support needs of individuals across different areas in their life (Schalock et al., 2019, Tasse et al., 2013). Additionally, while severe ID is seen as an impairment with a biological cause, classification systems acknowledge that restrictions and limitations that are experienced by people with severe ID are inherently linked to their immediate environment and the wider societal level (Schalock et al., 2007). For example, the WHO has developed the International Classification of Functioning, Disability and Health (ICF) alongside the ICD to highlight the multi-dimensional nature of disability. The ICF stresses the interaction between the person's impairment and their immediate and wider environment. Environmental factors are seen as impacting on people's engagement in activities, their levels of involvement and participation in life, thus creating disability (Foley et al., 2012). However, while an emphasis on the role of environmental factors and processes has been an important and positive one, I am aware that classifications and diagnoses are part of a system that produces labels and categories, determining who gets access to funding and medical or therapeutic support (Schalock et al., 2007). This is also the case during transitions, where assessments about levels of need are linked to available budgets and services. I hope it will become clear during the presentation of my findings and later in my discussion that I am not uncritical of the role assessments and classifications play. The dilemma I believe is an old one: How can we avoid categories and embrace individual differences without eliminating the ability to talk about inequalities experienced by a group of people, if we are not able to define them as a group?

To create a common understanding this thesis uses conceptualisations put forward by the WHO (2018) and AAID (2010) to adopt the following definition of severe and

profound ID: Severe and profound ID is defined by extensive impairments of skills and developmental delay in cognition, language, social and adaptive abilities. This encompasses individuals who need daily, continuous help and supervision across different environments in their life, are non-verbal or use very limited forms of speech. Thus, there is a high degree of dependency on others, and reliance upon others to make decisions on behalf of the individual. Individuals are affected from birth and it is a life-long condition, where a high level of support needs remains stable throughout the individual's life. It is important to remember that this will encompass a range of individuals with differences in needs and abilities. Some individuals will be physically very able but their impairments in communication, social skills and cognition will require them to have high levels of supervision, while others will have additional physical impairments or exceptional health care needs. The latter group is commonly referred to as people with profound and multiple disabilities (PMLD).

2.1.2 Prevalence

Prevalence rates estimate the number of people with a condition in proportion to the general population (McKenzie et al., 2016). The exact number of people with ID in Scotland is unknown but about 23 584 adults with ID were known to local authorities across Scotland in 2019, which equates to 5.2 people per 1000 people in the general population in Scotland (SCLD, 2019). There is no available data on the exact number of people with severe or profound ID in Scotland. This is due to a lack of detailed recording by most local authorities and public health bodies and inconsistency in the definitions and terms used (NHS GG&C, 2011, McConkey et al., 2019). Most studies that attempt to give an estimate report on the number of people with moderate to profound ID. For example, reviews of the adult population in two local authorities in England (of the Leicestershire and Brent register, as cited in NHS GG&C, 2011) and a study conducted in Greater Glasgow and Clyde (GG&C) (NHS GG&C, 2011) estimate the number of adults with moderate to profound ID to be 3.7 (Leicestershire, at age 20 and over), 3.9 (Brent, at age 16 and over) and 3.2 (GG&C) per 1000 adults. The number of people that are the focus of this study will be smaller, as the addition of people with moderate ID will include adults able to express their views and able to be independent in some areas in life, for example able to self-travel. A review of the Leicestershire and Sheffield register in England in 2009 focused on people with complex needs, who met the criteria of severe incontinence, severe behaviour

problems, at least partly mobile and non-ambulant (Institute of Public Care, 2009). The authors suggest a rate of 1.16 (Leicestershire) and 1.64 (Sheffield) per 1000 adults from the ages 25 till 89, with higher rates in young adulthood. While this estimate will be closer, the focus on severe behaviour problems will exclude others with severe ID that do not present with behaviour that is deemed challenging. More is known about the number of people with profound and multiple disabilities (PMLD). Their number is estimated to be 0.05 per 1000 in Scotland (Scottish Government, 2013), while Emerson et al (2009) estimated their number to be 78 in a population of 250 000 in England in 2009. Overall, the number of adults with severe and profound ID, who require social care services is increasing due to advances in medical care and an increase in life expectancy among people with ID (Emerson, 2009, Emerson and Hatton, 2008).

2.2 Historic overview: From institutions to care in the community

The 20th century has witnessed an immense shift in our understanding of and the way we relate to people with ID in the UK and other western countries. At the beginning of the 19th century people with ID were seen both as vulnerable and dangerous to society and the prevailing viewpoint was that people with ID were best placed away from society in life-long care (Atkinson et al., 1997, Mansell and Ericsson, 2013, Welshman and Walmsley, 2006). Many people were separated from their families and placed in institutions, where they were stripped of their rights. Inside institutions people's lives were controlled by institutional rules, without privacy and with many reports of abuse and neglect (Atkinson et al., 1997, Welshman and Walmsley, 2006). The now infamous Mental Deficiency Act and Mental Deficiency and Lunacy (Scotland) Act, labelling people with ID as idiots, imbeciles or feeble-minded, were passed in the UK in 1913 and remained in effect for 45 years (Egan, 2011).

In the 50s and 60s there was a growing interest in the lives of people living inside institutions, including people with mental health problems and people with ID. Sociocultural studies described inhuman practices (Foucault's 'Madness and Civilization', 1960; Edgerton's 'Cloak of Competence', 1967; Goffman's 'Asylum', 1961 and 'Stigma', 1963) and there was a shift in discourse filtering through to governmental and policy level. In 1959 the Mental Health Act was passed which advocated for

'community care' instead of institutional care for people with disabilities. The Act was influenced by a growing emphasis on human rights after World War II (Mansell and Ericsson, 2013, Welshman and Walmsley, 2006). However, throughout the 60s institutions continued to operate and little funding was made available to realize care in the community. Change slowly started to happen in the UK when a series of scandals became known to the public, leading to a significant shift in public policy in the 70s (Johnson and Traustadóttir, 2005). Simultaneously, disabled people became involved in the civil rights movement, including parents of people with ID (Parlalis, 2008). Deinstitutionalisation started to happen in the following four decades, but it was a slow and cumbersome process. In Scotland hospitals with provision for people with ID continued to open in the 80s and it took till the 90s for significant change to happen (Dalrymple, 1999, Mansell, 1999). The NHS Community and Care Act (1990) introduced the development of community-based health and social care services to allow for people to be supported in their own homes and local communities. This led to the closure of hospitals such as Gogarburn Hospital in the Lothian area in 1999, which had operated since 1924, and Lennox Castle Hospital in Greater Glasgow in 2002, which had been the largest learning disability hospital in Scotland, operating since 1936 (Dalrymple, 1999, Parlalis, 2008).

2.3 Where and how do adults with severe ID live?

In the UK people with the most severe disabilities, including people with severe ID, were among the last ones to leave institutional care and people with severe ID were often moved into larger residential-type services before local authorities began to develop services able to support people with severe ID in smaller settings, such as group homes (Emerson and Hatton, 1996). Most adults with severe ID now live either with family or in some form of supported accommodation (Ormston et al., 2017, Hatton, 2017). Supported accommodation can take the form of smaller group homes, but more recently there has been a shift towards single tenancies and core and cluster support in many local authorities in Scotland (Ormston et al., 2017). Core and cluster services consist of several tenancies in close proximity to each other, allowing people to live in their own flats while support is provided to all tenancies by the same provider. Additionally, a smaller number of people with severe ID in Scotland live in life-sharing communities, where people and staff live alongside each other (Scottish Government,

2013). Life-sharing communities usually comprise of several houses and workshops, where people with ID can work during the day, such as farms and craft workshops.

While the move to community care has been achieved for a majority of people, there are still people with ID who live in learning disability hospital units or in specialist residential care settings, often in out-of-area placements, meaning that people are moved to local authorities that are far away from their families and local areas to access specialist services (Hatton, 2017). This is because the health needs of some require specialised support that is not able to be delivered within their local communities, while for others local authorities have been unable to identify suitable accommodation and suitable providers, able to support people with complex health or behavioural needs (MacDonald, 2018, Mental Welfare Commission, 2016a). In her report on out-of-area placements in Scotland, MacDonald (2018) identified that among those in out-of-area placements who are supposed to return to their local areas, 72% had moderate or severe ID. She identifies a shortage of suitable accommodation and lack of skilled service providers, particularly around issues of challenging behaviour, as main reasons for out-of-area placements. Similarly, the transition into supported accommodation has been identified as more difficult and complex for people with PMLD due to lack of suitable housing and suitable support. People with PMLD often have complex physical disabilities, requiring housing that is able to accommodate specialist equipment and is wheelchair accessible. Thus, adults with PMLD are thought to be more likely to live in residential care services or with family carers than those with mild or moderate ID (Gauthier-Boudreault et al., 2017, Haddow, 2004, Gray et al., 2014).

In the following I will examine research that links different service models, social care practices and attitudes to the quality of care that people receive, before I explore research that explores the quality of life of people with severe ID. In the context of severe ID quality of life is largely facilitated by others, family members and professionals, and it is also influenced by services and resources that are available to people, the organizational culture within social care services, as well as activities available to people in local areas (Bigby and Beadle-Brown, 2018, Bigby et al., 2015, Simpican et al., 2015). Thus, the quality of care people receive directly influences their quality of life and both concepts are inherently linked.

2.3.1 Quality of care

Quality of care refers to the ability of social care services to support the wellbeing of people with severe ID. In their evaluation of different service models (dispersed housing schemes, residential care settings, therapeutic communities) Emerson et al. (2000a) found that dispersed housing schemes (community-based small group homes) were able to provide a more personalised quality of care. Residential care settings were reported to offer less opportunities for choice, social interaction and participation in community activities with higher risk of victimization of service-users (Emerson et al., 2001). Both dispersed housing schemes and therapeutic communities were associated with greater quality of life in relation to social networks available to people and their engagement in activities. Comparing residential care with dispersed housing schemes specifically for people with severe ID and complex needs, Emerson et al. (2000b) found that people living in housing schemes experienced significantly greater quality of life. Yet, interestingly the three studies by Emerson et al. (2000a, 2000b and 2001) also showed wide variation in the quality of care between services of the same model and research suggests that alongside service models, the organizational culture within services and staff attitudes significantly influence quality of care (Bigby and Beadle-Brown, 2016, Bigby et al., 2009, Becker, 2020, James et al., 2018). The provision of good quality of care has been shown to be difficult to achieve for adults with severe ID (Bigby and Beadle-Brown, 2016). People with severe ID rely heavily on the willingness of staff to provide support to enable them to participate in activities and to be involved in daily decision-making. Ethnographic researchers describe how people with severe ID can often experience low levels of support and engagement from staff (Hubert, 1991, Mietola and Vehmas, 2019, Talman et al., 2019) and research suggests that staff can struggle to believe that involving people with severe ID in activities or decisions is realistic or meaningful (Bigby et al., 2009, Bigby et al., 2012). Simmons and Watson (2014) write that

this appears to manifest, in particular, at the stage of adult transition where young intellectually disabled people are reported as not holding concepts of emergent adulthood and decision-making capabilities (p. 15).

Adulthood has transpired as a complex concept within research on the transition into adult services for people with severe ID (Redgrove et al., 2016). Differences between discourses on a policy level and actual practice have been identified. Rights-based concepts such as choice, inclusion and participation are now commonly used to

underline the work of governments and third sector service providers but they are seldom well defined and lack examples of people with severe ID (Bigby et al., 2009). Thus, while policies emphasise people's right to self-determination and involvement in decision-making processes, staff and family members often stress the person's vulnerability and their incapacity to make informed decisions (Murphy et al., 2011).

2.3.2 Quality of life

Quality of life (QoL) is a vast and complex area of research. For the purpose of this chapter I will focus on measurements that are commonly applied within the field of ID, I will question their value in relation to severe ID and introduce studies that propose an alternative perspective to QoL measures to understand the lives of people with severe ID. This will be followed by a closer examination of experiences of social inclusion, which is one of the core domains that is used within the QoL literature in the field of ID.

QoL has been reported to be poorer for adults with severe ID compared to those with mild or moderate ID (Kraemer et al., 2003, Lee McIntyre et al., 2004). QoL is most commonly measured across eight domains: interpersonal relationships, material wellbeing, emotional wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights (Schalock, 2004, Townsend - White et al., 2012). Researchers have questioned if standard QoL-assessments can be used in the context of severe ID. Assessments in the context of severe ID rely on proxy-reporting and some of the domains have been found unable to reflect what is important in the lives of people with severe ID. Particularly, the domains of self-determination, social inclusion, personal development and rights appear to be ambiguous when applied in practice (Lee McIntyre et al., 2004, Nieuwenhuijse et al., 2019, Simplican et al., 2015, Townsend-White et al., 2012). Some researchers suggest that qualitative approaches might be more appropriate to capture the QoL of people with severe ID than objective measures (Nieuwenhuijse et al., 2019). Qualitative studies have shown that a reconceptualization of QoL for those with severe ID might be more meaningful. Domains that have been identified to be relevant to the QoL of people with severe ID and currently not captured by standard assessments are: access to educational and therapeutic services to support health and the development of skills; access to

meaningful recreational activities; consistency in care and consistency in relationships (Gauthier-Boudreault et al., 2017, Hall, 2010, Lee McIntyre et al., 2004).

Research on social inclusion illustrates the complexities and ambiguities inherent in conceptualisations of QoL for people with severe ID. Social inclusion is often measured based on people's access to community settings (community participation) and the number of relationships people have within those mainstream settings (excluding family and professional networks). Yet, social inclusion can also be examined by exploring the quality of interpersonal relationships a person has in their life within private settings (Bates and Davis, 2004, Simplican et al., 2015). For example, Wilder (2008), who examined social networks in the lives of children with profound ID, found that within dyadic interactions between parents and children there is similarity of closeness and engagement for children with profound ID compared to typical developing children. In her study the family was described as the child's main setting where children experienced close relationships to other family members. Other networks identified by Wilder were predominantly professional settings such as school. Additionally, her study revealed a lack of connections between the social networks of children and other family members. For example, children were found to have relationships to others within their school but there was little overlap of relationships between the school and family setting. Furthermore, family members participated in systems to which the child with profound ID had no access to. This points to the nature of isolated environments and limited social networks that still exist for people with severe ID (Gauthier-Boudreault et al., 2019, Kamstra et al., 2015). However, while a lack of relationships with people outside the family and professional networks is often used as an argument to illustrate how people with severe ID experience social exclusion, researchers have also described how specialised settings, such as special education schools or day services, are able to offer people with severe ID experiences of intimacy, friendships and a sense of belonging (Hall, 2010, Power, 2013). During the school years children with severe ID are part of the same class setting for several years, offering children and young people a sense of connection outside the family environment and facilitating opportunities for peer-relationships. Additionally, most children and young people will have access to therapeutic services such as speech and language or occupational therapy through their schools. Once school ends many young people lose access to therapeutic

services (Gauthier-Boudreault et al., 2017) and research has reported a decrease in social interaction and peer networks (Small et al., 2013). Furthermore, research describes that within adult services provision is sparse, less reliable and relies on short-term funding with often high staff turnover (Hudson, 2006, Becker, 2020). In relation to vocational and recreational activities, adults with severe ID and their families usually have the choice between joining a day-centre or outreach support (Gauthier-Boudreault et al., 2019). Yet, following the austerity measures since 2008 many day-centres in local authorities have closed and there has been a move towards individualized packages of care for people with severe ID (Power and Hall, 2018). Questions have been asked if the move towards individualised support and outreach services has resulted in greater social inclusion or resulted in greater isolation of people, merely placing them in their local communities without an increase in interaction with the community and less support available to them (Malli et al., 2018).

2.4 Old age

This section will explore what is known about changes in people's health and their support needs as they are getting older. This will include an examination of people's access to health and social care services and the support people receive during the end of their lives.

2.4.1 Quality of care, health needs and access to health services

Older adults have been identified as the fastest growing group among people with ID (Emerson and Hatton, 2008) and there is now increasing interest in old age as a life stage (Grant et al., 2001). Throughout adulthood people with ID experience different life trajectories, without common markers such as employment and retirement (Power and Bartlett, 2019). Families often provide care and support for their children long into adulthood and this can result in the situation of aging adults being looked after by aging parents, with both experiencing an increase in support needs (Hubert and Hollins, 2000, Walker and Ward, 2013, Deville et al., 2019, Egan and Dalton, 2019). As parents age or pass away, siblings often take on caring roles and can become carers or advocates for their sibling (Coyle et al., 2014). However, there is also a group of older people with ID who are part of the generation that has experienced institutionalization and the subsequent shift to care in the community. Some of these

adults will have little family involvement, as they spent a big part of their lives living far away from their local areas (Grant et al., 2001, Hubert and Hollins, 2000).

Research suggests that people with ID age earlier. An increase in age-related conditions can happen as early as from the age of 30 for people with severe ID and complex needs and is often seen around the age of 50 for people with moderate or mild ID (Truesdale and Brown, 2017). As people's needs change questions arise about the kind of services needed to support adults with ID entering old age (Coyle et al., 2014). In a climate of austerity and funding cuts in the UK, studies report concerns about adequate care provision for both people with ID and older people (Hardy et al., 2005, Hayes and Moore, 2017, Power and Bartlett, 2019). Although people with ID now live longer, their life expectancy is still shorter than that of the general population, particularly for people with severe ID (Truesdale and Brown, 2017). Causes of death have been shown to differ for people with ID, and some have been linked to poorer access to healthcare and poorer experiences of assessment and treatment processes (Adams and Jahoda, 2019, Heslop et al., 2014, Truesdale and Brown, 2017, O'Leary et al., 2018). Research indicates that people with ID face inequality in relation to health care and are less likely to receive adequate services or regular health check-ups (Cooper et al., 2004, Emerson et al., 2011, Krahn and Fox, 2014). This is of particular concern in older age as people's health needs increase. Age-related conditions, such as cardiovascular disease, incontinence or immobility, are comparable to or higher than in the general population for people with ID. Higher rates are connected to co-morbidities such as epilepsy, particularly in people with severe ID, and specific syndromes that place people at higher risk to develop certain conditions (for example Down-syndrome and Dementia), as well as lifestyle risks associated with ID such as obesity and being physically inactive (Cooper et al., 2015, Grant et al., 2001). Dementia is more common in people with ID compared to the general population. Dementia has been found to develop at an earlier age and to be more common among all people with ID, not only those with Down-syndrome. The course of the disease and symptoms are similar to the general population, such as wandering, apathy, aggressive behaviours and sleep disturbances (Cooper, 1997, Gangadharan and Jesu, 2015). Dementia can place people at higher risk of developing depression, but signs of depression are often missed by those who support people with ID (Cooper, 1997). Similarly, mental health needs are often overlooked in people with severe ID,

who are at greater risk of developing mental health conditions as they are more likely to experience sudden life transitions, narrow social networks and lack of meaningful activities (Grant et al., 2001, NICE, 2018, Adams and Jahoda, 2019). Professionals can find it difficult to identify the onset of aging, dementia or mental health conditions and often changes in behaviour and needs are attributed to the person's existing disability-related impairments (Grant et al., 2001, Johansson et al., 2017).

2.4.2 Capacity and 'aging in place'

Within the population of people with ID entering older age a number of people will be assessed as lacking capacity to make informed decisions (Foster and Turner, 2007). This includes people with severe ID, but difficulties around capacity also relate to people with mild or moderate ID who develop dementia and experience a loss of capacity (Cleary and Doody, 2017). Providing care during the transition into older age that takes account of their needs and wishes can be challenging for services (McKenzie et al., 2019). The identification of best-interests is difficult in cases where adults have communication difficulties and where their wishes and views cannot be assessed with certainty (Wagemans et al., 2013). As individuals are deemed unable to make many decisions themselves, others, such as family members and professionals, make choices on their behalf. These decisions include where the person should live, medical treatment and decisions around end-of-life care (Adults with Incapacity (Scotland) Act 2000). Allowing people with ID to 'age in place' is now regarded as best practice and associated with higher levels of QoL (Webber et al., 2010) but it has been shown to depend largely on the skills and knowledge of staff and available resources, instead of the wishes of the person with ID (Webber et al., 2010). Services can struggle to support people in their home as their needs and associated risk increase, tensions that are reported within both the dementia and intellectual disability literature (Elliott et al., 2009, Lord et al., 2016, Webber et al., 2010). While services for older people can struggle to meet the needs of individuals with ID, ID specific services can find it difficult to meet age-related health needs (NICE, 2018, Redley, 2019). Lack of staff training has been identified as one of the main barriers to appropriate support for older people with ID (Crompton et al., 2020, Holst et al., 2018). Close collaborative practice between professionals with ID specific knowledge and those with specific knowledge about dementia, primary healthcare or palliative care has been identified as crucial to meet the needs of the person and enable them to stay

in an environment they are familiar with supported by people they know well (Cleary and Doody, 2017, Holst et al., 2018). Research with people with mild ID has given insights into their experiences of the aging process. People show an awareness of a change in their identity and report anxieties about end-of-life and dying (Kåhlin et al., 2015, McEvoy et al., 2012, Newberry et al., 2015). Yet, although research indicates that people are aware of the concept of dying, often staff seem to avoid talking to people about death as they are concerned that it will upset the person (Todd, 2004, Tuffrey - Wijne and Rose, 2017). This can result in people with ID not knowing that they themselves or their family members are dying (Tuffrey - Wijne et al., 2020).

2.5 Policies and legislative framework – the Scottish context

The last decades have seen a policy move towards inclusion, self-directed support and individualised services across the UK (Johnson and Traustadóttir, 2005, Power and Hall, 2018). Legislations promote for people with ID to be given more say about their lives, upholding values of choice, independence and user-involvement. This reflects a rights-based approach, which countries around the world have started to support by endorsing the Convention of Rights of People with Disabilities (CRPD). The CRPD calls for people with disabilities to be given the same rights than everyone else, tackling health inequalities, promoting educational and social inclusion, community living and strong user-involvement (The United Nations, 2006). The UK ratified the agreement in 2009.

This section will briefly discuss the legislative framework relevant to this thesis. However, before I introduce key-policies and legislations, I would like to stress that the shift in policies towards greater rights happened during a time of economic austerity, resulting in many cuts to local authority budgets. Thus, the move towards user empowerment went hand in hand with the scaling back of local authority services (Burton and Kagan, 2006, Power and Hall, 2018). In the UK, government expenditure on adult social care fell by 9% between 2009/10 and 2016/17 (Thorlby et al., 2018). In Scotland expenditure per head increased by 0.3% per year between 2008/09 and 2015/16. Prior to the financial crisis of 2008 funding had been increasing across the UK by around 5.6% a year. Thus, the small increase in Scotland was unable to meet

the increasing demand on adult social care, nor did it reflect rising living costs (Scottish Learning Disabilities Observatory, 2017). It has been suggested that the demand on adult social care will rise at an annual rate of 3.9% across the UK and that based on current government spending, this will result in a funding gap of 18bn by 2030 (Charlesworth and Johnson, 2018).

2.5.1 Doran Review and ‘Keys to life’

The Doran Review (2011), commissioned by the Scottish Government, was set up to investigate the provision for children and young people with additional support needs in Scotland. Transitions between services were highlighted as an area of concern, particularly the transition from school to adult services. The review raised concerns about a lack of cooperation between services such as school, social work, mental health services and adult social care providers. Parents reported a lack of accessible information about the transition process, their rights and options. Transition planning was reported to often start late, with a lack of involvement of young people in the planning process and a lack of accountability of who was responsible to support young people and their families once they had left school. Parents described their transition experience as *falling into a ‘black hole’* (Doran, 2011, p. 29).

In their ten-year learning disability strategy, ‘Keys to life’, the Scottish Government (2013) acknowledged the findings of the Doran review and set out the following recommendations in relation to transition practice:

- Transition planning must begin no later than one year before a known transition
- Schools must exchange relevant information with other agencies to develop a person’s transition plan
- Families and young people must be involved in setting aims and identifying possible options
- Access to post-school educational training and supported employment must be improved

Due to a higher complexity of support needs, the strategy recommends that transition planning for young people with severe ID should start earlier, if possible during the transition from primary to secondary school. Other transitions that are discussed by

the strategy are transitions into supported accommodation, as well as bereavement and the loss of family members. While 'Keys to life' proposes stronger efforts to include people with ID in decision-making processes and improve their quality of life, it acknowledges the mitigating effects of welfare cuts and the reform of the welfare state, stating:

The economic downturn continues to have serious impacts across Scotland, with levels of debt and financial problems remaining high (...) (p. 55).

Transitions continue to be highlighted as an area of concern and priority in the recently published implementation framework that sets out the priorities of Keys to life between 2019 and 2021 (Scottish Government, 2019).

2.5.2 Principles of Good Transition

In Scotland the Scottish Transitions Forum (2017) was formed to improve the transition experiences of young people and their families. The forum developed seven 'Principles of Good Transitions', which have been endorsed by many third sector organisations and local authorities across Scotland. The principles call for (1) transitions to be planned in a person-centred way; (2) for close coordination across services; (3) for planning to start at age 14 and for support to continue to age 25; (4) young people should get the support they need, which requires an understanding of the number of young people who require support, current levels of unmet need and an involvement of young people and their families within areas of service commissioning and strategic planning; (5) information needs to be accessible to families and young people; (6) families and carers need support; (7) and transition practice needs to continue to be evaluated across Scotland. The seven principles closely mirror transition guidelines from the National Institute for Health and Care Excellence (NICE, 2016), which recommend that young people and their carers are involved in service design, delivery and evaluation and for services to work closely together and share information.

2.5.3 Self-directed Support legislation

Self-directed Support (SDS) aims to give people who receive social care greater choice and control about their care. The Social Care (Self-Directed Support) (Scotland) Act 2013 obligates local authorities to offer people four options of how they would like to receive their social care support. The options include: (1) people receive

direct payments from local authorities and manage their budgets and arrange their support themselves; (2) people choose how their support should look like and local authorities or a chosen service-provider arranges the support and manages the budget; (3) local authorities choose and arrange the support; (4) a mix of the three options. (Audit Scotland, 2017)

2.5.4 Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act provides the legal framework on how to respond in cases where adults are deemed to lack capacity to make key decisions regarding their life. Guardianship is given to family members, significant others or local authorities where an adult is deemed incapable of making decisions about their own welfare and guardians can make decisions on behalf of the person, including decisions about where a person lives, their finances and their personal and medical care. However, guardianship does not negate an involvement of people with severe ID in decision-making processes and the Act itself promotes the autonomy of the person and their involvement in making decisions (Stevenson et al., 2009). Knowledge about the act and efforts to involve people who are deemed to lack capacity has been shown to be poor in areas, with frontline staff tending to stress the inability to involve people in decision-making processes (Bigby et al., 2009, Ramsey, 2005).

3. SYSTEMATIC REVIEW

The transition from school to adult services

This chapter presents my systematic review, which explored what is known about the transition from school to adult services for young people with severe ID. As I started my research with a focus on the transition from school to adult services, the systematic review was my first step into the topic of my PhD. Its findings informed the design of my first study and highlighted to me the importance of taking a life-course perspective to transitions. The review was published by the Journal of Applied Research in Intellectual Disabilities in 2018. The published journal article can be found in the appendix.

3.1 Background

The transition to adulthood for young people with ID has been highlighted as an area of significant importance (Doran, 2011, Foley et al., 2012, Hardy et al., 2005). It has been dubbed the ‘black hole’ of transitions (Doran, 2011) and research has highlighted the need to improve practice in the UK (Cox, 2017, Hudson, 2006, Stalker and Moscardini, 2012). Studies that examine transitions and involve the person with ID mostly include participants with mild to moderate ID (Daviso et al., 2011, Foley et al., 2012, Mitchell, 2015, Salt et al., 2019, Young et al., 2016) or do not differentiate in their findings between degrees of disability (Pilnick et al., 2011, Ward et al., 2003). However, lives and pathways of those with severe ID may differ due to higher support needs, dependency on others across the life course and difficulties in accessing further education or achieving employment (Foley et al., 2012, Gauthier-Boudreault et al., 2019, Hogg, 1999). Adulthood is usually defined by increasing responsibility, independence and work (Arnett, 2015) and emerging adulthood can highlight the tension inherent in the gap between the individual’s abilities, possibilities and the acquisition of adult status (Jacobs & MacMahon, 2016, Pilnick et al., 2011, Biswas et al., 2016).

The need to better understand the unique situation of individuals with severe ID transitioning to adult services has been highlighted by both researchers and policy makers (Doran, 2011, Foley et al., 2012, Murphy et al., 2011). In their review on the

transition from school to adult services, Foley et al. (2012) conclude that there is a need for future research to overcome the bias towards those with mild and moderate ID, as policy recommendations that are only based on what is known about people with mild and moderate ID will not reflect the needs and interests of those with severe ID.

3.2 Aim and scope of the review

The aim of the review was to critically examine what is known about the transition to adult services for young people with severe ID. In the case of young adults with severe ID, decisions regarding future support happen, typically, within the context of multiagency involvement that includes family members, statutory services, such as education, health and social work, third-sector care providers and others such as advocates (Hardy et al., 2005, Murphy et al., 2011). Thus, this review attempted to address the research question from an ecological perspective, in order to capture not only the perspectives of family members but also to incorporate findings in relation to the decision-making process of different stakeholders and organisational and cultural influences. To capture the complexity of the transition process and its impact on those involved, the review focused on qualitative studies.

3.3 Inclusion criteria

When and how transitions take place differs between and within countries. Furthermore, studies within this review were conducted at different points in time, spanning three decades of changing transition policies and service commissioning. Thus, the definition used was broad, including transitions from school to further education, respite, day and care provision. Although healthcare transitions are considered within some of the included studies, this was not the focus of this review. Essentially, the focus of this review was on young people ending school and being at the threshold to adulthood. Inclusion criteria were (1) studies published in English, (2) examining the transition process from school to adult services, (3) relating to severe or profound intellectual disability and presenting (4) qualitative data. To ensure that studies were meeting inclusion criteria 3, studies were not solely included on the basis of the diagnostic terms used but based on the description of participants and their needs and abilities. Studies that included a range of young people with differing levels

of disabilities were required to differentiate their findings specifically in relation to severe ID.

Throughout this article the term parents will be used to refer to all main carers that participated in the studies.

3.4 Search strategy

The systematic search was conducted between January and October 2017. The search comprised of electronic database searches, review of retrieved articles' reference lists, hand searching, contacting experts within the field, and the search of grey literature sources. Databases included were: Ovid, Social Work Abstracts, CINAHL, MEDLINE, PsychInfo, Sociological Abstracts, ERIC, ASSIA, Social Care Institute for Excellence SCIE. The following search terms were developed with support from an academic support librarian. They were applied to each database and combined using AND (table 2). Truncations were used to ensure the retrieval of different variations of the chosen terms.

Table 2: Search terms

ID specific search terms	Severe and Profound specific	Transition from school to adult services specific
(Intellectual or learning or development* or neurodevelopment* or cognitive or mental) and (handicap* or disab* or difficult* or impairment* or deficien * or incapacit* or delay or disorder* or retard*)	Profound or Complex or Multiple or Severe or Dual or Serious	transition or "adult service*" or adulthood or "adult life" or "post school" or "leaving school

Search Retrieval Protocols were used to document all searches and authors were contacted in cases where important information in relation to inclusion criteria was missing (see appendices). The search identified two publications by the same research team (Gauthier-Boudreault et al., 2017, Gauthier-Boudreault et al., 2018). It was found that both publications had significant overlap in the reporting of their results. Thus, the second article was excluded as a duplicate (Gauthier-Boudreault et al.,

2018), while its content was closely examined to complement findings of the included article (Gauthier-Boudreault et al., 2017). A flowchart of the search can be seen in Figure 2.

3.5 Critical appraisal of included studies

Included studies consisted of eight peer-reviewed journal articles, four academic theses, one book and one government report. Three studies^{2,4,5} used mixed methods; the current review only synthesizing their qualitative data. There were differences in the studies' methodological quality, with some providing little information about their analysis of qualitative data^{2,3,11,12,13}, with one study providing no information (Dee and Byers, 2003). Additionally, two studies provided little to no examples of their data^{2,4} to support their interpretations. Both of these studies did not use interviews but described the evaluation and implementation of projects to improve practice. As those two studies focused on collaborative practice and organisational influences, they were still included in order to enrich an ecological understanding of the subject, albeit with the caveat that they offered very little data that was possible to use within the review. All studies were critically appraised using the guidelines for appraisal of qualitative research developed by the Critical Appraisal Skills Programme (CASP, 2017). Eight of the studies were peer reviewed by a second, independent researcher. We were both in agreement in appraising seven of the eight studies. We differed in our appraisal of two categories for one of the eight studies. The study was discussed in more depth at a meeting between the two of us and an agreement was reached. An overview of studies and the quality assessment can be seen in tables 3 and 4. Surprisingly, there was no mention of ethical considerations for five of the included studies^{2,4,5,11,13}.

Figure 2: Flowchart of search process

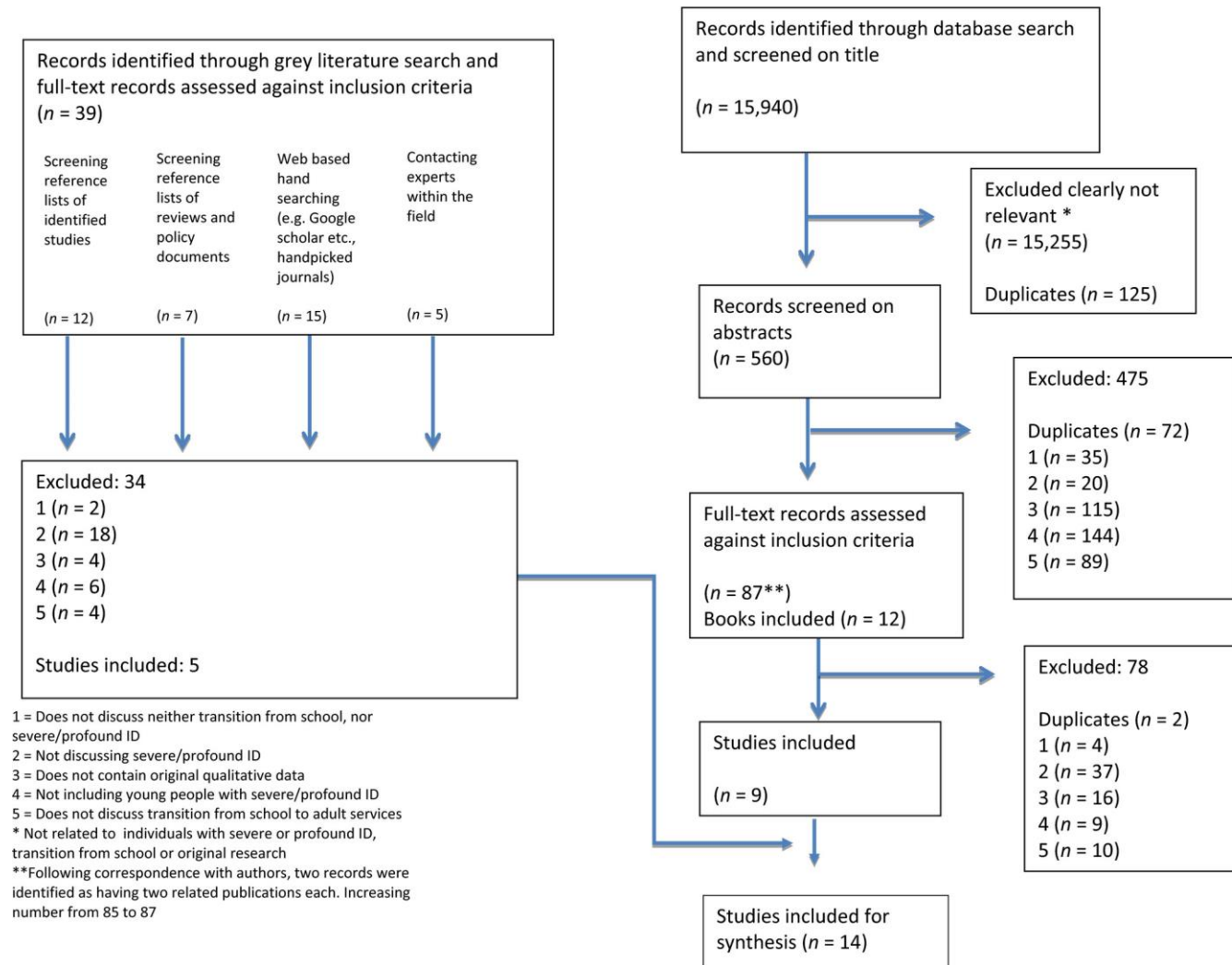


Table 3: Overview of included studies

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound ID)
1. Biswas et al (2017) UK	To explore parents' views of the transition of their child into adulthood	Recruitment was supported by various charitable organisations utilising non-probabilistic purposive sampling.	12 parents of children with severe intellectual disabilities (age 44-78) 8 mothers, 4 fathers 11 young people (age 19-29, one child 57*) *Data relating to this case was excluded due to age of child and indication that child did not meet criteria for severe or profound ID.	Interviews with parents using open-ended structured questions and non-directed probing. Grounded theory used to analyse data.	Identified an overarching theme of parents making comparisons with perceived norms of adulthood and the following themes: <i>Defining adulthood:</i> Using broad definitions of adulthood as starting point to understand transition. Differences in taking a chronological or developmental view. <i>Noticing adult development:</i> Identifying biopsychosocial changes within own children. At times difficulty to identify signs of adulthood or to support gap between emotional, intellectual and physical development. <i>Perceiving barriers to adulthood:</i> Necessity to rely on professionals. Continuing dependency of adult children. <i>Worrying:</i>

					Transition as a 'black hole'. Concerns about safety, risks and long-term future. <i>Making psychological adjustments:</i> Some parents encourage age-appropriateness while others continue to be accepting of children's 'child-like' interests. Other parents are a source of support, while some participants find it difficult to share their experience.
2. Carnaby et al (2003) UK	To evaluate the involvement of students with learning disabilities within transitions meetings and to facilitate and evaluate subsequent practice improvements	Case study of one special school. Evaluation of practice (phase 1) and 4 year follow up of implementation of recommendations (phase 2)	Phase 1: 15 students and their families (age 16 – 18; mild to profound ID) Phase 2: 12 students and their families (age 16 – 18; mild to profound ID)	Qualitative data includes observations of meetings, fieldnotes and reflection of themes present within decision-making process. No information on method used for qualitative data except stating that it included a review of main themes.	The following themes were identified in relation to severe or profound ID: Little to no participation within transition meetings. Lack of concrete future planning. Last year of school "waiting" for transition to day-centre. Transport important for parents. Use of creative methods such as video and photographs suitable to facilitate involvement of students unable to speak for themselves.
3. Cox (2017)	To inform improvements by outlining themes	Participants from five different local authorities within	29 families and additional consultation with	Meetings and interviews with families and professionals. Semi-	The following themes were identified in relation to severe or profound ID:

UK	and suggestions arising from experiences of transitions. The lived experience of young people and their families form the basis of the study.	Scotland. Recruitment through local organisations and services.	professionals and service managers. Young people (age 15-24) Disability: Ranging from 'high functioning' to profound and multiple disabilities. 10 cases were identified as meeting review definition of severe or profound in correspondence with author of study. Only data in relation to those 10 cases was included.	structured conversations. Use of questionnaires, charts, pictures and talking mats. Gives summaries of all 29 case studies, followed by discussion of themes. No mention of method employed to analyse data but uses 'bridges' (strengths) and 'cliffs' (weaknesses) to frame the narratives of cases and makes reference to 'lived experience' as underlying approach.	Need for an understanding of the whole family system and a life course perspective. Need for continuity within the co-ordination of transition. Need for professional guidance and detailed information. Need for partnership work across professional and family systems. Need for support and respect for parents and carers.
4. Dee and Byers (2003) UK	To improve quality of life for people with profound and complex learning difficulties during	3 year project working across four case study sites and involving a variety of stakeholders in the dissemination of	4 case study sites One specialist college, one sector college, one community-based	<i>Action research phase:</i> Working with 4 case study sites to identify areas of improvement.	The following themes were identified in relation to severe or profound ID: Often no transition procedures in place to support young people moving on.

	periods of transitions. To explore inclusive environments and to foster inter-agency collaboration and staff development	produced project material.	adult education and one social and employment services Dissemination phase: colleges, universities, schools, day centres, therapy services, students and families.	Interviews, fieldnotes, observations and focus groups. Using data to produce project material <i>Dissemination phase:</i> Working with organisations and individuals to explore how to improve service provision. No mention of method used for data analysis.	Further adult education can make a contribution to the lives of adults with profound and complex learning difficulties. There is a paucity of provision post-school, as well as wide regional variations. Provision is fragile, relying on short-term funding and/or committed individuals. An understanding of individual's unique communication behaviours is important.
5. DeZonia (2008) USA	To examine parent, teacher and institutional formulations of adulthood for students with profound developmental disabilities.	Recruitment through special educational schools with the researcher being the director and founder of one of the schools. Utilisation of stratified non random sampling.	8 trio's of students, parents and teachers. 8 teachers within public (2) and private (6) schools 8 parents (age 36-62) 7 mothers, 1	Multiple case study and triangulation of multiple methods. Interviews, educational documents (IEP, ITP) and governmental documents, fieldnotes and online newspaper blog*	The following themes were identified in relation to severe or profound ID: Parents, teachers and institutional settings have differing perspectives on adulthood and future adult lives for people with profound developmental disabilities. IEP and ITP goals are more consistent with teacher's views compared to parents and institutions.

			father, 6 white, 2 latino) 8 students (age 16-21) Disability: Autism (5), Cerebral Palsy (2), Down syndrome (1)	Cross-case, constant comparison, inductive analysis. *not referring to transition and therefore excluded from review. Referring to case study of public opinion in relation to individuals with profound ID	There is a need for information on future options for teachers and parents.
6. Doyle (2012) UK	To gain insight into the experiences of parents whose children are transitioning to adult services and to identify key themes relating to parents' experiences during the transition	Study conducted within an ethnically diverse outer London borough with participants from BME communities. Parents recruited through one special school utilising purposive sampling.	5 mothers of children with profound intellectual disabilities Ethnicity: Bangladeshi, Sri Lankan, African, Filipino, Caribbean/British 5 young people (age 17-18) Disability: Cerebral Palsy (3), Autism (1),	Interpretative Phenomenological Analysis (IPA) utilising semi-structured interviews.	The author identified the following themes: <i>Young Person's diagnosis:</i> Moment of diagnosis still very present in mothers' narratives. Young peoples' needs become more complex towards adulthood. <i>Experience of Transitions:</i> Anxiety about transition process and confusion about expected roles. <i>Planning for the Future:</i> Concerns about recent cuts and impact on transition. Worries about quality and suitability of adult provision. Difficulty to know what young people want themselves.

			Leigh's Syndrome Mitochondrial Disorder (1)		<i>Experience of Working with Professionals:</i> Positive and negative experiences of working with professionals. Parents would like smaller transition meetings and be guided more by professionals.
7. Dyke et al (2013) Australia	To explore the perspective of mothers on the transition to adult life for their children with Down-syndrome* compared to mothers of daughters with Rett- syndrome. *Data relating to young people with Down-syndrome was excluded due to indication that young people did not meet inclusion criteria of severe or profound ID.	Purposive sampling. Sample selected through two national databases. Participants from both rural and urban areas.	7 parents of 7 young adults with Down syndrome. 11 mothers of young women with Rett-syndrome (age 19-33) Living arrangements of young women with Rett-syndrome: 6 with family, 4 supported accommodation and 1 partly home and partly in supported accommodation	Qualitative semi-structured phone interviews. Transcripts were manually coded using content analysis.	Authors identified the following themes: <i>Adult roles assumed during the day:</i> Transition Process characterized by uncertainty with limited information. Need for strong parental advocacy. No involvement of the young person in decision-making process. <i>Accommodation:</i> Worries in relation to future living arrangements and wanting to outlive children. Difficulty to secure supported accommodation. <i>Quality of life:</i> Most mothers describe own QoL as poor. Concerns about own aging. <i>Living a 'good' life:</i> Most mothers believe daughters live a good life.

					<i>Family impact:</i> Loss of safe environment of school and loss of other informal support networks and impact on maternal employment. Importance of transport.
8. Gauthier-Boudreault et al (2017) Canada	To propose realistic solutions to meet the needs of adults with profound intellectual disability and their families during and after the transition to adulthood.	Recruitment through intellectual disability rehabilitation centres utilising both convenience and snowball sampling.	14 parents of young adults with profound ID* (age 18-26) *based on APA definition	Descriptive, interpretative approach employing two semi-structured interviews. First interview to document different solutions and second interview used to validate and deepen the researcher's understanding of themes.	Authors identified the following themes: <i>Need for informal support:</i> Lack of information on procedures and responsibilities and lack of information sharing between stakeholders resulting in increased demands placed on parents. Need to develop a step-by-step transition plan starting 3 years before end of school. Responsibility of coordination should be placed with a professional. <i>Need for material support:</i> Lack of full-time day care services. Need to increase available places and to continue to support learning and development of skills. <i>Need for cognitive support:</i> Lack of understanding of profound ID within services resulting in unsuitable approaches and lack of stimulation. Need for training for staff.

					<i>Need for emotional support:</i> Lack of emotional support for parents during the transition process. Need to create parent support groups with professional input.
9. Haddow (2004) UK	To investigate the experiences of family carers in relation to Future-Needs-Assessments, transition process and provision of post-school placements. To explore practice improvements and to develop criteria for good quality provision and services.	Four cases from one local authority in Scotland utilising purposive sampling.	4 Families with children with profound and multiple learning disabilities (young people age 19-27) 5 Professionals: Education, Social Work, Health, Third sector.	Multiple case studies. Interviews with data presented as 4 case stories. Interviews analysed using 'interpretative-descriptive' method informed by grounded theory. Uses interview data and analysis of documents to develop focus groups focusing on practice improvements. Policy discourse analysis used to analyse documents.	The author identified the following themes: <i>Information:</i> Lack of information about assessments and the transition process <i>The FNA process:</i> At times not all stakeholders present at meetings. At times there is a lack of knowledge about the young person's needs or available services. Little progress is made between meetings <i>The transition period:</i> Difficulty of arranging transition with post school places being identified late or not at all. <i>Post-school provision:</i> Lack of available provision. Provisions often not able to meet complex healthcare needs. Provision is short term and there is unclarity about long term future provision.

				Uses nominal group technique to develop quality criteria for adult provision.	
10. Hollinrake (2005) UK	To gain an understanding of how parents make sense of the transition time and to explore if there are differences within coping.	Recruitment supported by one local authority social care services department utilising purposive sampling. Study area rural and predominantly 'white'.	20 parents with children with severe intellectual disabilities. 15 mothers, 1 father, 4 parent pairs 18 Young people (age 18-29) Disability: cases with challenging behaviour (11), epilepsy (9), autism (5), health difficulties (4), physical disability (3), non-verbal (4), very limited communication (5), limited verbal abilities (9)	Phenomenological approach. Semi-structured interviews and fieldnotes. Grounded theory used to analyse data.	The following themes were identified in relation to severe or profound ID: <i>Overarching theme:</i> Being a main carer is demanding, enduring, time-consuming and intense. Three different groups identified across participants in relation to their views, adaptation and coping styles. Groups are named (1) Balanced and resilient, (2) Self-reliant and rational and (3) Preoccupied and overwhelmed.

11. Hubert (1991) UK	To understand the worlds of families caring for young people with severe learning difficulties. To describe the lives of families with a focus on respite services and families who choose to keep their children at home.	Participants from one county in southern England. Participants recruited through special schools, residential care services and social and health care professionals	20 families. Young people (age 15-22) Disability: Some described as immobile, some mobile with additional behaviour problems. Study heavily based on involvement with mothers.	Ethnographic research study. Researcher spend two years with families. Several in-depth interviews, observations, participating in daily life activities and interviews with others such as professionals. 5 families selected as in depth case studies. Study discusses a variety of themes. Data only included in relation to transition.	The following themes were identified in relation to severe or profound ID: Transition from children respite service to adult services is traumatic and distressing for parents and young people. Too abrupt. Young people's needs increase in adulthood while there is less respite provision. Provision is often uncoordinated, less reliable and haphazard. Age-appropriateness seems more important within adult services than individual needs. Parents would like smaller units with groups of young people with similar ages. Parents worry about the future and being aging carers.
12. Murray (2006)	To explore the experience of parents and their care work during	Study advertised in newsletter of a support and advocacy	8 mothers with daughters with severe or profound	Qualitative semi-structured in-depth interviews.	The author identified the following themes:

Australia	transition to adult services	organisation. Other participants recruited through subsequent snowball sampling. Participants from two different regions: Melbourne and regional Tasmania.	intellectual disabilities. Young women: (age 16 to 24) Disability: majority neuro-developmental disorder. All with intellectual and physical disabilities.	Transcripts coded by key themes.	<i>Leaving school: Transition or continuation?:</i> Leaving school connected to moving setting and not to an increase in independence or attainment of adult status. Transition from paediatric to adult health care additional big change and less respite services available. Future worries in relation to dependency across lifespan. <i>Finding a suitable program:</i> Demanding and stressful time for parent. Difficulties in accessing right information. <i>Families' involvement in developing new programs:</i> Several mothers developed individualised programs to meet their daughters' needs and challenge expectations to fit into existing services.
13. McIntyre et al (2004) USA	To describe and evaluate the quality of life for adult children with severe intellectual disabilities from their mothers' perspectives in	Participants recruited through Southern California Regional Centres.	Mothers (mean age 49.4) of 30 young adults with severe ID.	Dominantly qualitative methodology utilising two interviews and open questions alongside a standardised Quality of life questionnaire.	The following themes were identified in relation to severe or profound ID: A qualitative analysis using interviews was more meaningful to form an understanding of QoL for this population as reported by mothers in contrast to using the standardised QoL questionnaire during the first interview.

	relation to their current life stage of transitioning into adulthood Focus of the study is more on quality of life rather than the transition process.		Young adults* (age 18-24) Disability: Cerebral Palsy (11), Down syndrome (1), Autism (4), ID only (14) Not all young people in the study fit the definition of profound or severe ID with some described as having a paid job or being able to express their views to some extent.	Interviews recorded verbatim and coded.	Mothers highlight the need to meet their children's basic needs, to offer activities that keep their children busy and to provide social interactions in providing a good quality of life. Family is important for young people. Communication difficulties, challenging behaviour and health concerns impact on young people's QoL. Independent living skills are valued by mothers whose children have exited school. There is a tension between the hope for independence and young people's needs and abilities. The QoL of the young adult is interdependent with parent's QoL.
14. Young-Southward et al (2017). UK	To explore transition experiences of young adults with intellectual disabilities and their parents. To identify health and	Recruitment through special education schools and organisations providing support to individuals with ID across the West of Scotland.	26 young people (age 16 -27) Disability: mild ID (7), moderate ID (4), severe (7), profound (8)*	Hermeneutic qualitative design employing interviews alongside behavioural screening and general health questionnaire (SDQ and EQ-5D)	The following themes were identified in relation to severe or profound ID: Increase in challenging behaviours for some young people on leaving structured school environment leading to exclusion from services and thus alleviating lack of routine and activities.

	wellbeing implications.		23 carers, 20 mothers, 2 fathers, 1 grandfather and 1 grandmother 6 young people with severe ID present during interviews in the other cases of young people with severe or profound ID interviews only with carers. *based on Vineland adaptive behaviour scale-II	Semi-structured interviews with young people, their carers or both. Thematic analysis deploying emic and etic coding categories.	Parents struggle with the widening gap between their children's abilities and adult norms such as independence. Thus the transition is perceived to be primarily organisational instead of developmentally. Parents envision caring for their children into old age but hope for the attainment of some independence such as a move to supported accommodation for their adult children in the future.

Table 4: CASP assessment

Study	Aims and purpose	Suitability of qualitative design	Link between aim and study design	Participant selection	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Strengths and Weaknesses
Biswas et al (2017)	++	++	+	++	++	++	++	++	++	++	Detailed account of analytic process and ethical considerations. Coherence within all aspects of study. No discussion on why grounded theory was chosen. One adult child a lot older than others recruited. No discussion of impact of choosing an age range from 19 to 57.
Carnaby et al (2003)	+	++	+	+	++	0	0	+	+	++	Involvement of different stakeholders.

											No mention of ethics and little information on the research process and the process of qualitative data analysis. No information on overall number of participants meeting severe/profound definition. From eight meetings recorded only one meeting with student meeting inclusion criteria.
Cox (2017)	++	++	+	++	+	+	++	+	++	++	Inclusion of young people with severe or profound ID within study through visual methods and spending time. Little information on data collection and analysis.
Dee and Byers (2003)	++	+	+	+	+	0	0	0	+	++	Involvement of different stakeholders.

											Lack of detail in relation to data collection and analysis. No mention of ethical considerations and no example data presented. Article limited to do justice to scope of project. Other articles connected to project have quantitative focus and were consequently excluded.
Dezonia (2008)	++	+	++	++	++	++	0	++	++	++	Involvement of different stakeholders. Reflective of researchers' own role. No mention of ethics. Poor discussion on using quantitative analysis alongside dominantly qualitative design while comparing parent/teacher thinking and IEP and ITP goals

Doyle (2012)	++	++	++	+	++	++	++	++	++	++	Focus on BME communities. Strong coherence within all aspects of study. Four participants had English as an additional language. Interviews were conducted without a translator present. Difficulties in conducting and transcribing the interviews were noted by the researcher
Dyke et al (2013)	+	++	+	++	++	+	+	++	++	++	Aims not clearly stated and no discussion on link between research aim and method chosen.
Haddow (2004)	++	++	++	+	++	++	+	++	+	++	Involvement of different stakeholders. Researcher reflexive of own role as a mother of a young woman with profound ID.

											Little information on the recruitment process and no mention of ethical approval.
Hollinrake (2005)	++	++	++	++	++	++	++	++	++	++	Reflexive account of the research process given with an in depth discussion of ethics. Coherent study throughout.
Hubert (1991)	+	++	++	+	+	++	0	+	++	+	In depth reflection of author's own involvement as researcher. Research involvement over two years. There is a lack of information on recruitment, data collection and analysis and little use of existing literature. No mention of ethical considerations.
Murray (2006)	+	++	++	+	++	+	+	+	+	++	No clear statement of research objectives. Little information on analysis.

McIntyre and Kraemar (2004)	++	+	+	++	++	0	0	+	++	++	Discusses the issue of proxy reporting. No mention of ethics. Little information on data analysis. As not all participants and themes met the inclusion criteria only a small amount of data was included for the review.
Young-Southward et al (2017)	++	++	+	++	++	0	+	++	++	++	High credibility of findings with high degree of consistency found in identified themes. Use of quantitative questionnaires alongside qualitative interview not discussed. Only small amount of data relevant for review.

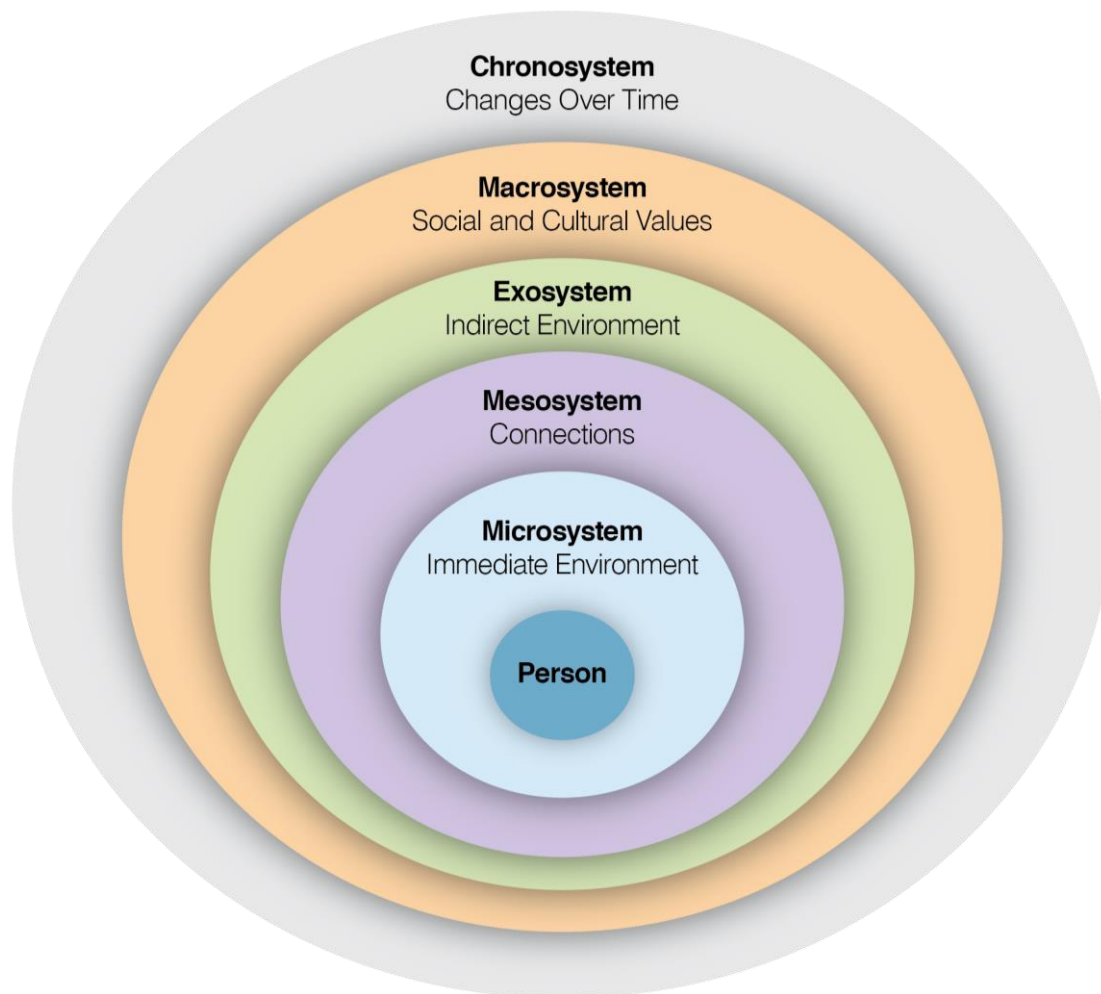
Gauthier-Boudreault et al (2017)	++	++	++	++	+	+	++	++	++	++	Very comprehensible and coherent study throughout One participant was unreachable for second interview.

3.6 Data analysis

Framework analysis was the chosen analytic approach to synthesise findings of the 14 included studies. Framework analysis was developed in the 80s in the UK to synthesise evidence in relation to policy questions (Ritchie and Spencer, 1994). It involves the use of an a-priori framework that is suitable for answering the review question and using it as the basis of coding evidence (Ritchie and Spencer, 1994). By combining inductive and deductive approaches it is able to explore predefined themes of concerns that have been developed within the focus of the review (Parkinson et al., 2016, Snilstveit et al., 2012). In the analytic process the framework is modified in response to the evidence reported, so that the final product is a revised framework that may include both modified themes and new themes that were not captured in the initial framework (Ritchie and Spencer, 1994, Stuart et al., 2017). Framework analysis will be discussed in more depth in the following methodology and methods chapter.

To aid an ecological exploration of the topic Bronfenbrenner's (1979) model was used to synthesise findings across studies (see Figure 3). Bronfenbrenner's framework sees the individual surrounded by different levels or systems, like a set of Russian dolls. The person is placed at the centre, surrounded by the Microsystem, which describes immediate environments of which the person has direct experiences, such as the family setting or school. The Mesosystem describes a level further removed and includes the interactions between different Microsystems, such as interactions between school, parents and social work. The Exosystem is still further removed and the person will not have direct contact with influences from this level. It includes, for example, policies or service commissioning in local areas. The Macrosystem describes the societal context the person lives in and includes cultural values as well as the political and economic climate. Lastly, the Chronosystem locates the interactions between people and their wider environment within time, acknowledging that people's circumstances change (Bronfenbrenner, 1979).

Figure 3: Bronfenbrenner's model



Qualitative data was extracted from all 14 identified studies. This included not only original data but themes and meanings that were highlighted by authors. Due to issues of feasibility only results sections of the included government report, PhD theses' and the book were extracted. Yet from included journal articles also abstracts, introductions and the discussion sections were included as authors made at times references to the results throughout the article. The ecological framework was systematically applied to the findings and themes proposed by the authors were set aside. The framework codes and sub-codes were applied to the findings using NVIVO qualitative analysis software (Version 11). Thus, the existing model acted as the base that was built upon, changed, reduced and combined within the process. Throughout the process the development of the framework was documented, and changes were applied to all studies continually. Towards the end of the analytic process a second

researcher used the framework and applied it to a selected sample of the data and the final application of the framework was discussed with the second researcher and both my supervisors.

3.7 Findings

Overall, studies reflected the variety of needs and heterogeneity of abilities in young people with severe ID. The samples ranged from individuals with complex health care needs and limited mobility, to young people who were physically very able but who required constant support and supervision within daily life. The latter group was often described as being on the autistic spectrum. Sample sizes ranged from 4 to 26 participants. The majority of studies utilised interviews to explore the transition process through the perspective of parents. A minority of studies explored the perspectives of different stakeholders and therefore were able to add to an ecological understanding. One study explored the views of parents within black and minority ethnic (BME) communities (Doyle, 2012): a gap within the literature of ID and across the included studies. Studies that included participants with mild to profound ID^{2,13,14} provided less relevant data than those with an exclusive emphasis on severe ID. Additionally, in most studies researchers only collected data at one point in time even though transitions are processes that can span many months and years.

How to involve young people with severe ID in the research process emerged as a problem across studies. In most studies, young people themselves were not involved in the research process and choices made about the involvement or exclusion of young people as participants were not discussed by the majority of studies. The lack of involvement of young people in the transition process appears to be mirrored in their lack of involvement in the research process. Yet, four studies were able to give presence to young people's lives and identity within the narratives of their studies. This was achieved by in-depth case studies and descriptions of the likes and dislikes of young people (Cox, 2017, DeZonia, 2008, Hubert, 1991, Haddow, 2004). One study described the use of art, pictures or Talking MatsTM (Murphy and Cameron, 2006) to involve young people directly in the research process (Cox, 2017), while Hubert (1991) and Haddow (2004) described spending time with young people and family members during the research process.

In summary methodological gaps seem to exist in relation to (1) the absence of multiple perspectives, even though the transition process involves multiagency decision-making, (2) a lack of involvement of young people and adults themselves and (3) a lack of focus on transitions as processes.

Themes across ecological levels

Bronfenbrenner's ecological framework was considered suitable to synthesise findings. Yet, notably one change required to be made to the framework during the analytic process. It appeared more appropriate to have the family, as opposed to the young person, at the centre of the framework. This might partly be explained by the designs of the included studies, as all studies relied predominantly on descriptions of the young people as seen by parents. Often, when reviewing, it was challenging to understand if addressed wishes and needs related to young people or to their parents. Therefore, it was decided to take the whole family as the first system. Additionally, at the beginning I believed that the chronosystem could be useful to capture the transition as a process over time. However, during the systematic review it became apparent that time was a more important theme, spanning the whole life-course of young people and their families from the time of birth and diagnosis to the far future when parents might cease to be able to care for their adult children. An incorporation of the theme of time facilitated an understanding of the transition within the whole life-course of the person and his/her family. Thus, it was decided that the immediate decision-making process of ending school and starting adult services was better captured within immediate family systems (Micro and Meso).

An overview of the a-priori and a-posteriori framework can be seen below (tables 5 and 6). Subthemes comprised environments and processes that were identified as influences within different ecological levels.

Table 5: A-priori framework

Master Theme
The Individual
Microsystems
Mesosystem
Exosystem
Macrosystem
Chronosystem

Table 6: A-posteriori framework

Master Theme	Subthemes
The Family	The young adult Parents Quality of life
Microsystems (Changing Networks)	Ending school Perceptions of adult services Additional networks
Mesosystem (Decision-making and Collaborative Practice)	Choice and information Roles and Relationships Involvement of the Young Person
Exosystem (Organisational context)	Coordination of services Budget and funding processes
Macrosystem (Society)	Culture Politics and economy
Chronosystem (A Life course Perspective)	From past to future

Themes relating to the first three systems were discussed by more studies than, for example, cultural or political influences. Themes relating to the family system showed the greatest complexity and content provided. Other themes such as the organisational context were widely mentioned, but the degree and depth of elaboration was less. Participants appeared to acknowledge the role and importance of 'wider' ecological systems, while not being deeply involved in them and having little information about how they worked.

3.7.1 THE FAMILY

The first two subthemes describe findings in relation to young adults and parents separately, while the third theme 'Quality of life' explores the interdependence of the young person's needs and needs of the family as a whole.

The young adult

Difficulties with communication, and the question of how to involve young people and access their views, were highlighted as problematic by participants across all studies. However, the need to understand and engage with individuals was emphasised in eight studies^{2,3,4,5,8,9,10,11}. These studies highlighted the importance of attuned and consistent relationships, valuing the unique and subtle communication of individuals. Adolescence and the move into adulthood had the potential to result in an increase of support needs, in relation to health needs, mental health or behaviour that challenges. For example, while young people physically matured, they became larger and stronger and care tasks as well as behaviour that challenges were more difficult to handle for carers. The gap between young people's intellectual development and their emerging sexuality was described as a concern within three studies^{1,3,10}.

There was some fluctuation in both parents' and professionals' accounts that described small developmental steps towards adulthood and more independence, while also acknowledging the consistency of needs of young people and seeing them as "eternal children" (DeZonia, 2008).

There's something that's still inside saying he's my little boy. It's a bit peculiar and you don't have the normal signals to tell you this child has grown up. (Hollinrake, 2005)

In relation to developmental processes that were observed by participants, this related to greater abilities in choice making and life skills, comprising small steps for example learning to carry a laundry basket (Biswas et al., 2017).

Parents

In the majority of studies, parents were acting as main carers. Parents' responsibilities involved daily care tasks such as personal care, medical care, facilitating meaningful activities and advocating on behalf of the young people. Parents also managed collaborative practice with involved professionals such as social workers, teachers, health professionals and third sector agencies or respite services. Mothers accounted for the clear majority of participants in the study sample.

Consistent, or increasing care demands within young adulthood were at once described in the context of parents becoming older and being less able to meet all the needs of young people. In five studies, parents described how the birth of their children had taught participants a new perspective on life and the deep love inherited within the relationship.^{3,5,9,10,11}

Quality of life

QoL of the young people was framed around meeting basic healthcare needs, providing activities and space for social interaction and stimulation. The responsibility to provide adequate QoL appeared to heavily rest on the family, especially mothers. Concerns about the QoL of parents dominated the analysis and was discussed by all studies except the two studies whose focus was not on parents^{2,4}. Offering a high QoL for their children seemed to negatively affect parents' own QoL. Parents were struggling with a lack of sleep and little time for themselves. Siblings were only mentioned in four of the studies^{3,4,9,10}, and parents seemed to try to discourage siblings to feel responsible to take on caring roles.

Moving out of the family home was discussed in nine^{3,5,6,7,9,11,12,14} of the studies and in six studies^{1,3,7,11,13,14} some young people lived in supported accommodation or residential placements, but this was the minority of cases with most young people living in the family home. There were variations in families who wished their adult children to move out of the family home, advocating for their children's right to

independence, while, at times simultaneously, parents had little trust in services to be able to adequately care for their children. Two studies described that some parents felt their own QoL had increased once their children were looked after outside the family^{7,11}, while other participants reflected on their perceptions of poor quality of care within residential or supported living services^{5,6,11}. A wish for more support outside the family lived alongside parental worries of risk and safety. Those fears seemed to stem from media coverage, but also direct experience of adult services:

There are horror stories about care homes and things, with abuse, and the worry was if she goes away and she's abused, how would she be able to tell us? Because if she went very quiet, that wouldn't be her, but then the carers don't know her. So they wouldn't pick up on it either. (Biswas et al, 2017)

The thought that parents would have to continue to provide substantial care until the end of their lives was described as a difficult process by some participants.

It's a daunting feeling because ... the older they get the more reality hits that you're like 'I'm going to be a carer for the rest of my life'. (Young-Southward et al., 2017)

There was too little data to make any judgment on types of accommodation in relation to quality of services but the need for trusting relationships with qualified staff was emphasized by parents in eight studies^{1,3,5,8,9,10,11,12}.

3.7.2 MICROSYSTEM

Subthemes included 'Ending school' and 'Perceptions of adult services' and captured the process of moving from school to adult services. 'Additional networks' described systems that had an influence on participants' experiences of transitions. There was a significant overlap with the previous theme 'Quality of life', which discussed the impact that leaving education and starting adult services had on the quality of life of both parents and young people.

Ending school

Ending school related to a feeling of loss. This was described in relation to the loss of a focus on learning and therapy services, and the loss of a well-known environment. As previously stated, uncertainties about young people's future lives increased anxiety, worries and stress for families.

I was really scared ... it was a really emotional time and because you are leaving this environment that you've been a part of for 15 years. (Dyke et al., 2013)

Perceptions of adult services

Participants described a change in approach in adult services, and there appeared to be a conflict between adult norms, which may be encouraged within adult services, and their children's developmental age. Studies described that within adult services young people either accessed home-based services, outreach services, day centres or a mix of the above. Parents expressed worries about adult provision compared to the school environment in relation to programs, peer-networks, equipment and hours offered. For young people with challenging behaviour^{3,5,6,10,11,13,14} or complex medical needs^{3,9,11} there appeared to be fewer services able to meet their needs.

Parents described an ideal adult placement as centre-based with small, same-aged groups, that facilitated learning and skills, and that was available 4 – 5 days per week, staffed with caring and qualified staff. Transport stood out as a topic^{3,7,9,10,12} and there seemed to be issues to secure transport funding, while parents described transport as highly important for them to be able to continue to work and offer them respite.

Additional networks

The move to adult day or supported living services was accompanied by other transitions, such as the move from child to adult respite services^{3,9,10,11,12}. This was reported to be a significant difficulty, as the amount of hours decreased in adult respite services compared to child respite, resulting in young people being at home more. Parents struggled with the reduction in respite, as the needs of young people remained stable and at times increased. Two UK studies described respite transitions happening at the age of 16 and before the end of school^{3,11}.

How will families barely coping in school years cope with reduced services in adult years? (Cox, 2017)

Additionally, the transition to adult health care services was emphasized as an additional and worrying change. The transition to adult health care was discussed in

detail by three studies^{3,9,12} and related dominantly to young people with complex health care needs such as epilepsy.

Other parents were seen as a welcome support system for families, especially in relation to sharing information on processes, existing services and the offer of emotional support. Yet, a few families spoke about feeling socially isolated and feeling that the behaviours of their children were not understood or accepted within their communities^{1,5,6,7,9}.

It's not well understood out in my community you know- when they see him behave bad they don't always accept he's disabled. (Doyle, 2012)

3.7.3 MESOSYSTEM

The Mesosystem comprised three themes in relation to decision-making and collaborative practice.

Choice and information

Across all studies, a lack of options and choices was described; this was one of the strongest themes in relation to the amount of content that was provided by all studies. Parents and, in a few instances, also professionals, such as education⁵ and social work professionals^{3,12} felt that there was a lack of guidance and information about the transition process. Many parents suggested that a list of available local services would be instrumental in supporting them to understand options and choices.

Give us a directory of resources and processes. We have no time to run around doing research. (Cox, 2017)

Lack of choice was linked to parents accepting 'inadequate' offers as they felt they needed to work with what was available.

I have got to make a compromise if you like that it is not what I would really want but until I can get what I really want we have just got to accept that this is the only thing that is there for her. (Murray, 2006)

Roles and Relationships

There was variability across studies describing the quality of collaborative practice. Tension between parents and professionals was identified as a barrier to successful transitions, while some parents spoke of individual professionals as their main support system. Tensions seemed to be related to the discrepancy between parents' perception of the extensiveness of needs of the young person, in contrast to services

and resources available to them. A difference in perspective between parents and teachers was highlighted by DeZonia (2008) in relation to priorities in future planning. Meetings appeared to be arranged through schools, while budget and funding decisions lay with social work. Funding decisions appeared to be especially powerful in shaping the transition process. For example, even when parents started the planning process early, uncertainties remained if budget decisions were not made and last-minute budget decisions could result in periods without support for families. In most cases, parents were strong advocates for their children, visiting available services and advocating on behalf of their children. However, three studies^{2,6,10} were able to show a different perspective from families where parents felt uncomfortable acting in an advocacy role and taking the lead in working with professionals.

Involvement of the Young Person

Another strong theme was the lack of involvement of the young person within the transition process. Due to communication difficulties, young people were largely excluded, and parents acted on the behalf of young people. Parents based their decisions on the known preferences of their children. Only in Doyle's (2012) study did parents voice concern about their role.

*But I do look at him sometimes and wonder if he understands what happening?
- am I doing what he wants? (Doyle, 2012)*

The difficulty of facilitating participation of the young person was discussed across all studies, with four studies discussing possible means to facilitate participation; for example, through sharing videos and photographs^{2,4} in meetings or professionals spending time with young people^{2,8,9}.

I think it helped the [intellectual disability rehabilitation centre] that did not know her apart from a picture, but then they really saw her interaction, they really saw her strengths and limitations. (Gauthier-Boudreault et al., 2017)

3.7.4 EXOSYSTEM

Subthemes related to coordination of services, accountability within the process and budget and funding decisions.

Coordination of services

As many different professionals were involved in the decision-making process, participants asked for more transparency and clearer pathways to responsibility and accountability^{3,7,8,9,10}. Parents spoke about the need for continuous support throughout their children's lives and there seemed to be a need for services that were able to accompany them and plan for future changes.

We don't know what would happen or where she would go ... we've got an aged care facility and I look at that and think that could be our option which is a scary option. (Dyke et al., 2013)

Budget and funding processes

Families struggled to understand how budget decisions were made and this seemed to increase tensions between families and local authorities. An increase in individualised and self-directed support appeared to have potential to allow parents to create a care package they found most suitable, able to facilitate support that was more flexible and person-centred. At the same time the management of organising individualised packages was described by some parents as demanding and stressful and some current packages appeared to not be able to cover what families would ideally like.

Complexity of managing personal care team under SDS – 'needs the skills of running a small business.' (Cox, 2017)

3.7.5 MACROSYSTEM

This theme encompassed data that related to cultural norms and values and the current political climate. Both themes were only tentatively sketched and especially within the realm of politics and economy there were only a few excerpts of data across studies that described participants' views and experiences of this theme.

Culture

Societal norms of adulthood were seen in conflict with abilities and opportunities in the lives of individuals with severe ID. References to a 'meaningful' adult life were made but it often remained unclear how such a life could look like. Especially parents, and to a lesser extent professionals^{3,5,9}, seemed to feel a tension between recognising that young people had different needs and were following different life paths, while at the same time hoping for or working towards the attainment of some 'normality'. This

'normality' for young people was viewed as having peer groups of a similar age or living out with the family at some point in the future.

Oh, I wish....and you're breaking down crying because you think what the hell do you buy him... if he'd been alright you'd be buying him his car now, you know, and all you can think of is a rattle or something. (Hollinrake, 2005)

Thus, this theme expressed a discrepancy between 'typical' development and young people's continuing dependency on the family.

The social worker kept saying to us all the time, 'of course you're not responsible for him anymore', I sort of joked with her when she said 'you're not responsible' and I said 'oh good, does that mean I can, I can nip off to the cinema then and just leave him here?' and she says 'oh no of course not'. (Biswas et al., 2017)

Two studies^{5,6} described how religion and faith offered support to parents and this was highlighted particularly within Doyle's study that focused on BME communities.

Politics and economy

Policies were described as promoting values such as autonomy and self-determination and were not able to capture the experience of those supporting individuals with severe ID. Families felt that they were not seen as a priority by governments and left alone with the responsibility of care. Within a difficult economic climate available support and services seemed to decrease.

3.7.6 CHRONOSYSTEM: A LIFE-COURSE PERSPECTIVE

Participants spoke of transition as an ongoing process and anticipated further transitions due to the changing needs of the individual and family, ongoing reviews of care provision or services ending their support for young people by their mid--twenties. There was a clear need to understand the continuing dependency of individuals into the far future. At the same time, development was also present within some studies and young people were described as learning and changing. Concerns about the long-term future dominated the narratives of parents and was discussed within nine of the included studies. The experience of diagnosis and early childhood on one side^{5,6,9,10,11}, and thinking about the long-term future and their own aging at the other side^{1,3,5,6,7,9,10,11,12,14} framed the stories of parents. The biggest worry of parents related

to what would happen to their children once they were unable to continue to be strong advocates.

3.7.7 Relationships between themes

During the analytic process I became interested in the relationship between themes across the ecological levels. Thus, the data were also explored with a focus on influences of one level to another. As a starting point I looked at the overlap of themes, examining extracts of data that were coded to more than one ecological level using NVivo (Version 11). Then I went back and looked at the data line by line to look for descriptions of relationships. An overarching theme of discrepancy emerged in relation to the experiences of families, the needs of the young person and wider ecological levels. Policies and societal values emphasizing independence and self-determination seemed to stand in contrast to lifelong dependency. Additionally, a discrepancy seemed to exist between an organisational context that conceptualised the transition as an event, while parents asked for an understanding that acknowledges their lifelong and continuing needs. However, relationships between systems were only tentatively sketched and studies did not provide detailed information on how different systems interrelate. Nonetheless, this does highlight an important issue of the extent to which high-levels policies in this area influence the outcomes for young people with severe ID.

3.8 Discussion

The transition from childhood to adulthood is often an exciting time in the lives of typically developing young adults. It is characterised by growing independence, leaving school and entering the world of employment or further education. It is a time when young people explore their identities, and relationships with others, outside the family, become more important (Arnett, 2015, Wehmeyer and Webb, 2011). This gives a stark contrast to the experience of the transition to adulthood for young people and their families in the studies included in this review. The experience of 'difference' has been highlighted by others (Klotz, 2004, Simmons and Watson, 2014, Ward et al., 2003) and can lead to ambiguity for those supporting adults with severe ID (Bigby et al., 2009, Dunn et al., 2007, Hubert, 2011). This reflects findings of my MSc study (Jacobs and MacMahon, 2016) where I found that the views of siblings illustrated this tension between difference and normality, of being both a different family, and being

just like any other family. It seems as if the experience of 'difference' is more prominent in this context compared to the literature on mild or moderate ID and ambiguities remain of how adult life does and should look like for people with severe ID (Mietola et al., 2017). This adds to the importance for research to differentiate within the spectrum of intellectual disability (Foley et al., 2012).

Organisational and societal influences were described by most included studies but remained on the periphery of parental experiences or views. Those studies that incorporated professional perspectives alongside parental ones were able to illustrate organisational barriers and facilitators in more detail. For example, Cox's (2017) report described organisational barriers that correspond to a similar study by Hardy et al. (2005). In their comparison study on transitions for young people with intellectual disability and older people who suffered a stroke, Hardy et al. (2005) found that inter-organisational complexity, overlapping responsibilities and historic underfunding of adult social care acted as barriers to successful transitions. Hardy et al. (2005) found that the availability of resources and available options seemed to be particularly influential in relation to those with severe ID and that transitions were viewed as points in time rather than a continuous process. I updated my search in September 2020 and applied the search terms to PsychInfo, Medline and ASSIA looking for new research papers that had been published since 2017. I was unable to identify any new publication that met the inclusion criteria but a study by Gauthier-Boudreault et al. (2020) on the transition experience of Canadian parents of children with fragile x-syndrome described that the transitions in their study were characterised by a lack of early planning, lack of meaningful activities and limited opportunities for social participation. People with fragile x-syndrome usually have some degree of intellectual disability, which can range from mild to severe but cases of young people with severe ID were not highlighted in the paper. Additionally, a recent study by Pearson et al. (2020) which looked at the transition experiences of young disabled people in Scotland, including young people with physical impairments and young people with mild ID, documented a lack of real choice and identified that most barriers to successful transitions were related to organisational practices and cultural attitudes and values. Furthermore, the authors criticised a view of transitions as one-off events. Thus, both studies highlighted the role of structural barriers, mirroring findings of this review.

During the analytic process, the decision was made to have the family in the centre of the framework, as opposed to the young person. This might reflect the lack of involvement of young people within the research process but might also point to the centrality of the family network in the lives of people with severe ID (Kittay, 2001, Kruithof et al., 2020, Ryan, 2020). Interestingly, studies highlighted similar concerns and barriers although the points in time of data collection spanned from the end of the 1980s to early 2017. Moreover, included studies encompassed five different countries and hence it is likely that the economic and political context varied between studies. Yet, similarities were more striking than differences within participant's accounts, illustrating that while increasing attention has been paid to the topic of transitions over past decades there seems to be little improvement in them.

3.9 Implications for own study design

Although the review was able to identify themes across ecological levels, this was mainly from the perspectives of parents. This review has shown that the inclusion of multiple perspectives could aid a better understanding of how decisions are made between members who have the complex task of identifying what is in the best interest of another person. Relationships between the different ecological systems were only tentatively sketched and this seems to be an important avenue for future research as the influence of wider systems does seem to have an impact on the transition experiences, while the question of how seems to be less well understood. Additionally, transitions are processes that can span many months and years, but in most studies researchers only collected data at one point in time. An experimental design able to capture changes and developments across time appears to be more suitable to describe the transition process as participants at the beginning of the process might have different views at the end of it.

How to involve young people in meaningful ways emerged as a problem across studies in relation to the transition process and the research process. Spending time with young people and the use of different data sources, including document reviews, observations, pictures and video seemed to be possible solutions to involve people within the research process. I will now consider these implications further while

introducing my research approach and the assumptions and principles that underlie my PhD.

4. METHODOLOGY

This chapter can be divided into two main parts. The first provides the theoretical and philosophical background to my PhD, while the latter examines how these theories informed my research design and methodological considerations. I will begin this chapter by introducing the three dominant theoretical models in the field of disability to discuss different viewpoints on what disability is and how we can best know about disability. I then introduce the two philosophical theories that informed my PhD, namely critical realism and ethics of care. I suggest that critical realism is able to bridge divides between the three models of disability that either focus on societal structures and environmental barriers, cultural beliefs and discourses or biological and medical approaches. Finally, I turn to ethics of care to try and develop a research approach to disability that is based on knowing relationally. In the second part of the chapter I introduce my research design and discuss how it is informed by critical realism and ethics of care. I introduce case study methodology from a critical realist position, which informed the design of my first two studies and I discuss how I drew on a number of additional research approaches from different disciplines to answer specific methodological questions and concerns in relation to: (i) the involvement of people with severe ID within the research process and their visibility within the research output, (ii) combining different data sources and information that relate to different ecological levels and that are based on multiple viewpoints, and (iii) my own role as the researcher, concerns in relation to power and ethics of representation.

4.1 Models of disability: ontological and epistemological considerations

Disability research has been informed by different theoretical positions, resulting in different approaches on how research is conducted. The positions reflect different perspectives on what disability is (ontology of disability) and how we can and should advance our knowledge of disability (epistemology of disability) to improve the lives of disabled people. The three dominant positions that theorise disability to date have been the medical model, social model and cultural model of disability (Shakespeare, 2013, Vehmas, 2010, Bhaskar and Danermark, 2006). Interestingly, within debates about ontological and epistemological questions within the field of disability there is a lack of theoretical work that focuses on people with severe ID (Vehmas, 2010) and

some researchers within the field of severe ID have criticized the three existing models as unfit to explain the complexity of the lives of people with severe ID (Jingree, 2009, Vehmas and Mäkelä, 2008, Vehmas and Watson, 2014, Vehmas and Watson, 2016).

In the following I will discuss each model in relation to the methodological perspectives they provide to understand disability, before introducing critical realism and ethics of care as alternative models.

4.1.1 The medical, social and cultural model of disability

Research on disability was for many decades framed within a medical model. Within this model disability is defined by behaviours, traits and cognitive and biological processes. Thus, the focus is on the person's impaired physical body and limitations are linked to the individual. As a challenge to the medical perspective, the social model of disability developed out of the disability rights movement in the 60s and 70s. It contributed to an important shift in people's understanding from seeing disability as a problem located within individuals towards a focus on societal barriers and disabling environments (Oliver, 2013, Shakespeare, 2013). The social model has been dominant in the UK and builds on a materialist perspective to explain disability. The model differentiates between impairment and disability. The impairment of the individual is not seen as the disabling factor. Instead the focus is on economic forces and physical environments and accordingly disability is located within socio-economic structures that limit a person's inclusion. (Oliver, 2013, Shakespeare, 2013) The cultural model of disability developed alongside the social model foremost in North America and takes a constructionist position, emphasising cultural representation over economic structures. Researchers focus on the role of ideas, values and cultural images within the construction of disability (Campbell, 2009, Mitchell and Snyder, 1997, Roets and Goodley, 2008). While it allows for a closer exploration of people's experiences than the social model, the main focus is on textual explorations of the concept of disability and the way dominant cultural discourses conceptualise disability, but the role of the impairment itself is often left out (Bhaskar and Danermark, 2006, Shakespeare, 2013).

Most theoretical writing within the social and cultural model draws on examples of physical disabilities and when intellectual disability is discussed examples

predominantly relate to people with mild or moderate ID (Vehmas, 2010). It seems that severe ID carries a complexity, which challenges the separation of impairment and disabling structures that is at the heart of both the social and cultural model. People with severe ID depend on others in profound ways. Financial and social independence is not possible and so severe ID challenges the aims of social and economic inclusion through the removal of environmental barriers. The cultural model seems to offer greater possibilities in the context of severe ID as it allows researchers to ask what a meaningful adult life is and how we conceptualize concepts such as inclusion, quality of life or adulthood. Yet, while it is important to understand how language and values shape how people are seen and how society relates to them (Goodley, 2001), there is a biological reality to severe ID and writers have criticized the negation of the reality of people's impairment within a social constructionist position (Vehmas, 2010, Shakespeare, 2013). For example, Jingree (2009) discusses feeling uncomfortable with taking a constructionist approach in her project that involved people with severe ID. Her argument is that if phenomena, including those of disability and disempowerment, are only given a socially constructed status, the physically experienced elements of human lives might be overlooked. Similarly, Simmons and Watson (2014) highlight concerns towards a social constructionist model in connection to research with people with profound ID. They state that although labels and stigma have a great effect on the lives of people with profound ID and their families, such constructions do not constitute the entirety of intellectually disabled people's lives. Similarly, Klotz (2004) writes:

Interpretations that only take these aspects into account, and which perceive the experience of intellectual disability as solely a product of sociocultural structures and constructions, disregard the fact that intellectual disability is also an ontological reality that makes a real difference to one's experience of being in the world. (p. 98)

An important question that is raised by Burr (2006) is: Does saying that something is socially constructed necessarily mean that it is not real? Here critical realism seems to be able to offer an understanding of the world that can encompass both.

4.1.2 Critical realism

Critical realism has been argued to sit in the middle between the two opposites of positivism and subjectivism, between a science perspective to research that tries to uncover factual and objective knowledge of the world and a belief that knowledge is

merely subjective and that there is no such thing as an objective truth (Burr, 2006, Shakespeare, 2013, Taylor, 2018). Critical realism differentiates between epistemology (how we know about the world) and ontology (the world as it exists), maintaining that while our knowledge of the world is always subjective, there is a reality to the world and being in the world, that exists outside of our knowledge of it (Archer et al., 2013, Collier, 1994). By differentiating between ontology and epistemology critical realism can encompass both, highlighting the subjective nature of human knowledge, as well as biological realities of human life. This allows researchers to acknowledge that the way we see and understand severe ID is socially constructed, but that people's impairment is real and will continue to influence their and their family's lives regardless of how many social barriers will be removed or values and ideas changed (Craig and Bigby, 2015, Vehmas, 2010). Thus, in relation to research within the field of intellectual disability, critical realism makes two assertions; firstly, it recognizes that intellectual disability is an ontological reality that has real consequences to the life of the person; and secondly it proposes that disability is best understood from a holistic and ecological perspective. Critical realism emphasizes the multi-layered nature of disability and asserts the importance of seeing it embedded within its historic, economic, cultural and social context (Bhaskar and Danermark, 2006, Maxwell, 2012, Vehmas and Mäkelä, 2008).

An increasing number of authors argue for the possibility of critical realism to bridge the divide between models by taking a holistic approach (Bhaskar and Danermark, 2006, Shakespeare, 2013, Stalker, 2012, Craig and Bigby, 2015). Prominent within Northern European countries, critical realism argues for a model of disability that is able to grasp *"the complex and multidimensional experience of disablement"* (Shakespeare, 2013, p. 7). Authors that draw on critical realism propose that research, which operates within current models, is at risk of reducing disability to either discourse, structures or biology, instead of seeing disability as multidimensional (Stalker and Moscardini, 2012, Vehmas and Mäkelä, 2008, Watson, 2012). Critical realism sees current models of disability as operating at different levels: the biological/individual, socio-economic and cultural level. It argues for a multi-level approach that is able to capture the strength of each model. For example, while the importance of stepping away from medicalising people, treating them as passive objects, has been an important achievement, leaving out the biological level can result

in practice in negating the importance of rehabilitation and specialist intervention aimed at improving symptoms and abilities (Shakespeare, 2013), which families of people with severe ID identify as vital for their quality of life (Gauthier-Boudreault et al., 2017). Shakespeare and Watson (2001) argue that disability sits at the intersection of biology and society and agency and structure, thus research within this field requires a methodology that is able to incorporate different levels. Researchers in the field of intellectual disability that take a critical realist position often work with different data source, include multiple perspectives and engage with different stakeholders (Mietola et al., 2017, Jingree, 2009, Mitchell, 2015).

4.1.3 Ethics of care – to know relationally

Ethics of care is a philosophical theory that emphasizes the importance of interpersonal relationships and care to understand human flourishing (Tronto, 1993). It stresses that vulnerability and dependence are central to human life. Relationships play a crucial role in understanding human life, as people are dependent on other people, as well as on the structures and systems that surround them (Kittay, 2001). Ethics of care stresses that as a society we are all inherently dependent on one another and therefore dependence is seen as the ontological reality of human life (Tronto, 1993). An increasing number of writers within the field of disability use ethics of care to theorise the lives of people with ID (Mckenzie and Macleod, 2012, Mietola et al., 2017, Porter, 2006), including the work of Kittay (2001) and Rogers (2016) who are both mothers of children with ID. An ethics of care perspective challenges liberal views that portray people as independent and rational beings, arguing that such views exclude people with severe ID and negate their humanness and personhood (Mietola et al., 2017, Kittay, 2001). While a focus on care and needs, as it is emphasised by ethics of care, has been criticised within disability research for continuing to portray people with disabilities as needy, vulnerable and passive recipients of care (Rogers, 2016), ethics of care writers argue that a turn towards needs is able to include people with severe ID within concepts of personhood and citizenship because it stresses that we are all fundamentally vulnerable throughout our lives. Being a person is not defined by being rational and autonomous but by having the capacity to be in relationships to others and to contribute to their lives (Kittay, 2001). This asserts that people with severe ID are fellow citizens who are able to form meaningful relationships and add value to the lives of others. Kittay (2001) argues that a re-focus on relationships affirms

that people with severe ID have voice and communicate, albeit often non-verbally. She writes about her daughter:

The shaping of one's own world is a gift that each individual possesses and that some make more use of than others. Sesha, in spite of all her limitations, makes ample use of this gift. To be with Sesha is to enter her orbit, to gain a glimpse of the world as she constructs it. (...) an individual's inability to articulate a "language" as publicly defined does not indicate a lack of anything to say. To fail to recognize that capacity is to deny an individual's personhood. When we do so, we cut ourselves off from those who enlarge our relational possibilities, and we lessen ourselves as persons. (p. 568)

Thus, the task of researchers is not to 'give voice' but to explore if the person has relationships to people that are able to listen (Rogers, 2016). It also emphasises the role of advocacy in facilitating the involvement and inclusion of people with severe ID and the need for researchers to work closely with those who know the person well and understand them.

Drawing on ethics of care has several implications for conducting research. While ethics of care explores care relationships, it is not only concerned with people's immediate relationships and private lives. On the contrary, ethics of care advocates for the importance to lift care out of the private sphere and explore its place within the wider socio-political context. Thus, similarly to critical realism, it takes an ecological perspective. In her 'care ethics model of disability', Rogers (2016) outlines three spheres of caring: the *emotional caring sphere*, where love and care are psycho-socially questioned, the *practical caring sphere*, where day-to-day care is carried out, and the *socio-political caring sphere*, where social intolerance and aversion to difficult differences are addressed (p. 2). Thus, she stresses the importance of research to explore the interactions between people's experiences (emotional caring sphere), practices within people's microsystems (practical caring sphere) and the wider socio-economic context. Additionally, ethics of care helps researchers to think about the research process as relational, focusing on relationships between researchers and participants and thereby addressing research privilege and ethics of representation (Brannelly and Boulton, 2017). Values and morals that are advocated by ethics of care translate into the research relationship, including a commitment to be attentive, responsive, responsible and respectful (Tronto, 1993, Mietola et al., 2017). Furthermore, a focus on the relational nature of research emphasizes that people are

different, and that people will have different knowledge and views based on their different experiences of life. Therefore, ethics of care calls for a *collective approach to make sense of the world together* (Brannelly and Boulton, 2017, p.345). This means that my epistemological position is based on a belief in *collective meaning-making* (Simmons and Watson, 2014, p. 135). Instead of taking a constructionist view to meaning-making that emphasises the role of the researcher in constructing knowledge, I concur with Simmons and Watson (2014) that it is important to involve significant others in research that engages with people with severe ID to draw on their expertise and learn from them about the person and their way of communication. Moreover, transition processes involve various people and I wanted to develop a methodology that was able to reflect multiple perspectives on the same phenomena to capture the interdependence of families, professionals and wider systems. As Simmons and Watson (2014) state, a recognition of the relational and interdependent nature of human lives translates into a methodological approach that focuses on collective narratives and complex networks of families and communities, instead of individual accounts.

4.2 Research design: linking the personal with the social

One of the aims of my PhD was to explore the interaction between different ecological levels and to deepen my understanding of socio-economic influences on transitions. I decided to draw on case study methodology, as this allowed me to explore the intertwinement of individual lives and macro-social aspects through the story of individual cases. Additionally, it allowed me to use multiple data sources and to include the perspectives of different people who were involved in the life of the person with severe ID and in the transition process. This enabled me to explore different layers and include multiple perspectives, working closely with the relationships that were present in the life of the person with severe ID, as well as relationships between families and professionals. An overview of my research approach can be found below (table 7).

Table 7: Overview of research approach

Research paradigm	Conceptual frameworks	Research design	Data sources
Critical Realism and Ethics of care	Ecological framework	Multiple case studies (study 1 & 2)	Interviews, Observations, Documents
	Life-course perspective	Interviews with social care professionals (study 3)	Individual interviews and Group interviews

Conducting observations and meeting the person with severe ID helped me to include an account of their lives. Additionally, my interviews with family members, teachers and health and social care professionals involved a focus on their relationship to the person and their understanding of the person's way of communicating and being in the world. Study three of my PhD involved interviews with social care professionals only, but similarly to the first two studies interviews focused on the relationships between participants and the people they supported. Reviewing policy and strategy documents provided me with an understanding of the wider service provision context, while my interviews with professionals helped me to understand how those informed their practice. However, interviews with professionals also highlighted other processes and factors that influenced their work. Thus, contrasting policy documents with my interviews helped me to understand what was missing from official accounts (Ledger, 2012). Combining an understanding of policies and the wider service provision context with an exploration of people's experiences helps to illustrate how people's everyday lives interact with the socio-economic and organisational systems that surround them, but it also offers the possibility to explore contradictions and tensions between policy and practice (McKee, 2009a). For example, in their project on housing governance and practice, McKee (2009b) found that not all welfare professionals adhered to the top-down policy discourse and often acted differently to prescribed practice. Thus,

taking a critical realist stance, McKee (2009a) argues for the benefit of research that combines an understanding of wider levels with accounts of people's everyday life experiences to reveal the messiness of actual practice. Similarly, Welshman and Walmsley (2006) discuss how first-person accounts from people with ID and those closely involved in their lives can highlight gaps between policy and practice. As Ledger (2012) writes:

Lived history accounts contribute to more history through personal and service details that only insider stories can give, but are also anti-history in telling a richer, more complicated account of the past than that contained in official policy or service records (p. 32)

While case study research informed the overall design of study one and two of my PhD, I also drew on the knowledge of other research approaches to think carefully about how to work with different data sources, how to keep the person with severe ID at the centre of my research and concerns in relation to my own role and issues of power. Diverse qualitative methodologies have been used in disciplines such as sociology and anthropology for many decades, with a strong awareness of the role researchers play during the data collection and analysis process and drawing on knowledge from different disciplines has been helpful to enrich research within fields such as psychology (Smith, Harre and Van Langenhove, 1995). In the following I will introduce case study methodology from a critical realist position in more depth, before discussing how vertical case studies, framework analysis, ethnography, life-story research and Seidman's narrative profiles further complemented my methodological approach.

4.2.1 The case for case studies

In the past case studies have been criticised for being poorly defined (VanWynsberghe and Khan, 2007) and being merely descriptive (Flyvbjerg, 2006). Descriptive case studies can often be found in reports as boxes that are placed next to quantitative data or theoretical discussions. In this context they are used to give an example from practice and present the reader with a summary of what has taken place (Flyvbjerg, 2006, Yin, 2003). Yet, in numerous disciplines case studies have been used in more complex ways to produce in-depth knowledge of multifaceted phenomena, allowing researchers to explore complexity in detail (Jindal-Snape, 2016, Yazan, 2015, Yin, 2003). Case studies are used across disciplines to produce different kinds of

knowledge, including psychology, counselling, educational and organisational science. They are used to evaluate practice in the form of case reports; illustrate an intervention or treatment to facilitate learning; build and test theory; identify concerns in particular fields or areas of practice and highlight the need for change; as well as to communicate with the general public and to make them aware of certain phenomena or areas of practice (Flyvbjerg, 2006, McLeod, 2010, Vavrus and Bartlett, 2006). The motivation behind this study lies somewhat between wanting to identify critical issues within current practice, hoping to further develop and understanding of transitions as multidimensional processes (Jindal-Snape, 2016), as well as finding a way to communicate to a wider audience how life is like for people with severe ID and their families at times of transitions.

Case study research sits well within a critical realist framework as case studies are able to facilitate an exploration of processes over time and across different layers (Easton, 2010, Eisenhardt, 1989, Maxwell, 2012, Miles and Huberman, 1994). Additionally, they are able to encompass a focus on specific contexts, as advocated by ethics of care (Rogers, 2016). Case studies are able to illustrate the complexity of a situation and to highlight the political, cultural and economic context through a bottom-up perspective (Maxwell, 2012, Merriam, 1998). The intertwining of individual lives and macro-social aspects is explored through the story of particular cases, in this study the transition journeys of six individuals with severe ID. An in-depth exploration of single cases can help readers to gain a better understanding of how the world works by embedding contextual influences in the concrete doings of people (Erickson, 1977). As McLeod (2010) states: (...) *'it is at the level of the case that the operation of different factors can best be observed'*. (p. 3)

An additional strength of case studies is the use of different data sources. Researchers are able to follow converging paths of inquiry and look at the phenomena from different angles (Miles and Huberman, 1994, VanWynsberghe and Khan, 2007). Stake (1995) claims that knowledge learned from case studies is different from other research knowledge. He describes it as more vivid, concrete and sensory compared to more abstract approaches to qualitative research. Similarly, VanWynsberghe and Khan (2007) argue that case studies are able to *'give the reader a sense of being there'* (p. 83). Thus, in the context of research that involves marginalised groups, the

shift towards writing about the lives of people is also a political one, as it allows readers to become witnesses to the existence of people whose lives are largely hidden from mainstream society (Rodriguez and Jacobs, 2020).

4.2.1.1 Case study research involving people with ID

Case studies are a common methodology within research in the area of ID, particularly when researchers want to include the person with disabilities in the research process. This is illustrated well within research on the social history of learning disability, which is largely presented in the form of case studies and life stories of the lives and experiences of individuals, contextualised in their historical context (Atkinson et al., 2000, Mitchell et al., 2006, Rolph et al., 2005). Case studies allow researchers to include people with severe ID in the research process, as well as making them visible within the presentation of findings. Case studies often work with detailed and thick descriptions based on observations and fieldnotes, which allows researchers to capture complexity and for people's lives to become visible (Ledger, 2012). Equally, the four studies in my systematic review that included accounts of the lives and experiences of young people all utilised case study methods (Cox, 2017, DeZonia, 2008, Haddow, 2004, Hubert, 1991). Furthermore, in the context of research on educational or healthcare transitions, case studies are often used as they allow for an exploration of multiple perspectives, following the journey of individuals, as well as their close support networks such as families, professionals and friends. Thus, case studies seem beneficial to capture the multidimensional nature of transitions (Jindal-Snape, 2016). Again, this was also apparent in the systematic review, where case studies were able to portray the influences of macro-social influences on the lives of people and their families (Cox, 2017, DeZonia, 2008). Thus, I hoped that using case studies would ensure that young people and adults would be present in the research process of this study compared to previous studies.

Once I started to plan my research in more detail, I became aware of the complexity of what I wanted to achieve. The central challenge that presented itself to me was how to combine an exploration of multiple perspectives and wider influences with a commitment to involve people with severe ID and keep them at the centre of my research. I felt that only drawing on case study methodology was not enough to prepare me for my research and that I needed to widen my knowledge to ensure I was

going to be able to address the ethical complexities of my study and the multi-layered nature of disability and transitions. The lives of people with severe ID and their families are closely intertwined with organisational practices and wider socio-economic spheres and research methodologies need to be able to capture the multidimensional nature of disability (Rogers, 2016). Researchers within the field of severe ID often draw on theoretical positions and methodologies from different disciplines to explore different layers and engage with ethical complexities. They argue that not one methodology, one approach or one paradigm is able to encompass the life worlds of people with severe ID (Avery, 2020, Mietola et al., 2017, Simmons and Watson, 2014). I agree with this assertion and in the following I will introduce and discuss other approaches that complemented and informed my research. None of the approaches by themselves seemed able to address all what I wanted to achieve. For example, drawing on ethnography and life story research helped me to deepen my understanding of ethical complexities and my own role within the research process but I needed to draw on vertical case studies and framework analysis to become clearer about how to explore different ecological levels. Thus, in the following I will reflect on what each approach was able to add to my research.

4.2.2 Drawing on ethnography

In their ethnographic study, Mietola et al. (2017) explore conceptualisations of how ‘a good life’ looks like for adults with profound ID who live in group homes. Their project involved joining the lives of adults with profound ID for 3-4 months, recording observations and fieldnotes, conducting interviews with professionals and families and reviewing key-documents such as care plans. Based on their experience the authors argue for the benefits of ethnographic research to involve people with severe ID in research. While acknowledging that researchers will be unable to directly represent the ‘voices’ and views of people with severe ID, they describe how ethnographic research is able to increase people’s knowledge of how their lives look like. Referring to Atkinson (2015) they argue that ethnographic research is essentially linked to ethics, as it includes a commitment of the researcher to convey ‘*the full complexity*’ (Atkinson, 2015, p. 172) of the lives of people who are otherwise overlooked, while being aware of the researcher’s own role in interpreting and representing those lives.

Ethnographic research classically involves a long-time involvement and an in-depth description and theorizing of a particular social or cultural world (Harrison, 2018). The importance of reflexivity within fieldnotes is central to ethnographic research, something that can often be overlooked by authors that write about case study research (White et al., 2009). Through the use of fieldnotes researchers have the possibility to address their role in representing and interpreting their data by using the first-person account and sharing with readers their experiences of the data-collection and analysis process. Data from different research methods is often combined through a rich and thick description that can include extracts from fieldnotes, observations, as well as interviews with others or a narrative re-telling of someone's experience (Flewitt et al., 2009, Gleason, 1993, Hubert, 1991, Simmons and Watson, 2014, Tuffrey - Wijne and Davies, 2007). Drawing on ethnography helped me to guide my thinking of how to combine different data sources and how to include an account of the young people and adults in my study, while being transparent about my role in writing that account. Being transparent about my role in the process of data collection and data interpretation was always going to be important to account for the power imbalance of doing research with people with limited verbal communication.

While it was helpful to draw on ethnographic research, I realised that similarly to case studies within the field of ID, ethnographic research mostly focuses on the experiences of individuals (Hubert, 1991) or observed social interactions between individuals and their immediate setting (Avery, 2020, Mietola and Vehmas, 2019, Simmons and Watson, 2014) and thus wider ecological influences are often left out. Yet, my study aimed to situate the transition experiences of people with severe ID within larger socio-economic processes, addressing questions of power, participation and rights.

4.2.3 Drawing on 'vertical case studies'

Vertical case studies '*situate local action and interpretation within a broader cultural, historical, and political investigation (...) with a commitment (...) to micro-level understanding and macro-level analysis*' (Vavrus and Bartlett, 2006, p. 96). This is achieved through an exploration of national policies, legislation and documents that describe the legislative and organizational context as well as engaging in ethnographic

fieldwork at local sites (Bartlett and Vavrus, 2014). Thus, vertical case studies are able to explore gaps between policy and practice, as they are able to compare what should be happening with the actual practice of what is happening (Crossley and Vulliamy, 1984, Vavrus and Bartlett, 2006). The fieldwork within vertical case studies is closely connected to ethnographic approaches to case studies but usually this relates to the investigation of sites such as schools, communities or government organisations (Bartlett and Varus, 2014), instead of focussing on processes that have a person at the centre. Drawing on vertical case study research helped me to better understand my reasons for choosing an ecological framework as well as helping me to develop an understanding how local fieldwork could be combined with an understanding of policies and organisational practices.

4.2.4 Drawing on framework-analysis – utilising an ecological perspective

In case studies conceptual frameworks are often used after an in-depth exploration of each case, to synthesise data across cases (Srivastava and Thomson, 2009). One analytic approach that can guide an analysis based on conceptual frameworks is framework analysis (Ritchie and Spencer, 1994). Framework analysis has been briefly introduced previously in the systematic review chapter. It involves the use of an a-priori framework as the basis of coding data. Its strength is that it allows for a theoretically driven analysis of the data (Satherley et al., 2017). By combining inductive and deductive approaches framework analysis allows researchers to explore predefined themes of concerns, in this case an ecological understanding of transitions, while remaining receptive to unforeseen and unexpected findings (Parkinson et al., 2016). It allows the researcher to ground the beginning of the research within a clear conceptual framework, without excluding data that does not seem to 'fit' the framework during the phase of data collection and analysis later on (Ritchie and Spencer, 1994). This form of analysis helps to advance knowledge and theory by exploring new relationships and by being context-specific (Meyer and Lunnay, 2013). While the use of an ecological framework results in a step towards a thematic understanding of the data, it remains visible for the reader as to what case the data came from (Srivastava and Thomson, 2009).

4.2.5 Drawing on life-story research and Seidman's narrative profiles

Life story research (Plummer, 1995) and narrative profiles (Seidman, 2006) both aim to explore participants experiences by staying close to their own words and developing first-person accounts from interview data. Thus, they give researchers a powerful medium to communicate about people's experiences and lives. Not only participants make sense of their experiences through narrative and storytelling, but we as researchers and audiences do the same. Therefore, both approaches argue that using narrative as a way to analyse and to communicate can help to build bridges between participants, researchers and audiences (Plummer, 1995, Seidman, 2006).

Seidman (2006) developed his 'narrative profiles' while working within the fields of education and psychology. His aim was to share with readers the privilege of listening to people's stories. His approach advocates using a first-person account to develop coherent profiles based on interview data. He argues that this allows researchers to share the profiles with participants before moving towards a thematic analysis of the data, to check the accuracy of the crafted account and find out if there is any information participants feel uncomfortable with. Additionally, he states that using large sections from interviews and working with first-person accounts aids greater transparency as it opens up the interview material to readers (Seidman, 2006). Life story research has its origins within the fields of oral history, sociology and anthropology (Plummer, 1995). Similarly to Seidman's profiles, in life story research interview data is presented through first-person accounts of an individual's life (Henderson and Bigby, 2019). Researchers have argued that first-person accounts present an inclusive research method as they are able to present the stories of people whose lives are largely hidden, undocumented or given significance (Grove, 2012, Ledger, 2012, Stenhouse, 2014). Additionally, the approach encourages researchers to take the perspective of participants, therefore inspiring an analysis that is based on empathy and understanding of people's lives (Henderson and Bigby, 2019). However, using a first-person approach has ethical implications in relation to authorship (Stenhouse, 2014). While emphasizing the perspective of participants, the role of the researcher in crafting the accounts can be neglected. It is therefore important that researchers are transparent about their own role in crafting the accounts (Henderson and Bigby, 2019, Plummer, 1995, Seidman, 2006). Over the past decades life story

research has been increasingly used within the field of intellectual disabilities, particularly to provide oral histories and personal accounts of people's experiences of institutional care and the move towards care in the community (Atkinson et al., 2000, Henderson and Bigby, 2019, Ledger, 2012, Mitchell et al., 2006). There are very few examples of life story research being conducted with people with severe ID (Grove, 2012, Hewitt, 2000). Grove (2012) argues that people with severe ID have so far largely been excluded from life story research because many writers highlight the agency of participants to tell their own stories, which is not possible for people with severe ID. Drawing on principles of ethics of care, Grove (2012) argues for a method that emphasises people's relationships, focussing on the central role of families, to develop a collective approach towards telling stories that is inclusive of people with severe ID. She writes:

This recognition of mutual dependence is of clear relevance to an ethic of social inclusion that promotes interpersonal interaction and relationships as the fundamental mechanism for achieving social inclusion (...). (p. 346)

By drawing on the experiences and perspectives of people who know the person with severe ID and have interacted with them, it is possible to include an account of their lives. While it is not a first-person account, it is an account that draws on multiple perspectives. To highlight the collective nature of the approach I decided to refer to it as 'narrative conversations' instead of 'narrative profiles' within my method and findings chapter.

4.3 Concluding remarks

People with severe ID are largely excluded as participants from research. While there is a growing, close-knit literature on methodological matters in relation to research that concerns this group (Nind, 2013, Klotz, 2004, Ware, 2004), it is small compared to the literature on participatory research methodologies within the wider field of disability studies (Mietola et al., 2017). It seems that engagement with the lives of people with severe ID poses a challenge to traditional research methodologies (Simmons and Watson, 2014), as well as assumptions about what constitutes disability, personhood, identity and voice (Vehmas and Mäkelä, 2008). Most research positions are based on an understanding of humans as verbal, reflective and autonomous. Yet, as Simmons and Watson (2014) argue such taken-for-granted-assumptions cannot be made in the

case of people with severe ID. Research that aims to involve people with severe ID needs to be able to account for methodological complexities in relation to how to access their experiences and it needs to address ethical questions in relation to the role of the researcher, power and ethics of representation (Nind, 2008, Mietola et al., 2017). My research is informed by critical realism and ethics of care as my underlying philosophical positions. Ethics of care is founded on the understanding that human beings are relational in nature. Drawing on ethics of care helped me to be clear about the parallels of wanting to include people with severe ID within my research and focusing on how people with severe ID are involved in transition processes as the topic of my research. I recognised the importance to focus on the relationships people with severe ID have in their life to both understand and facilitate their involvement (Klotz, 2004). An ecological exploration of transitions as advocated by critical realism on the other hand helped me to explore different levels and to understand how they interact in creating disability. In the following chapter I will discuss how the combination of critical realism and ethics of care on a theoretical level and case study methodology in combination with the above named research approaches on a research design level, helped me to navigate through the challenges of developing a research project that (i) has ethical concerns at its heart by trying to include people who are deemed to lack capacity to make informed decisions and use little verbal communication, and (ii) aims to take an ecological perspective to transitions

5. METHODS

Picture this: During my research I visit the homes of six families, different in sizes, in atmosphere and location. Six family homes with pictures of children, as babies, toddlers, teenagers and now adults. I visit two schools and six adult services. Young people and adults, staff, noise, tensions, smiles, laughter, music, rooms to do craft, rooms to exercise, rooms to cook, rooms to relax, rooms to socialise and rooms to be alone. One service has locked doors, wide and beige corridors, open plan - clean and safe; one has a big open space where people come and go, a busy café that welcomes people from the neighbourhood; another is smaller with adults and staff working in groups. Two adult services with big wooden houses and gardens and workshops to do pottery or weaving. Two houses where people live supported by staff. I go to different offices with buzzers and locked doors and meet professionals at tables with files.

For my final study I spend two and four days at two different social care settings, communities where adults with ID often live into old age. I join meals, social activities and visit people's work placements.

Overall, I travel through six different local authorities in Scotland - north, east, south and centre. Three different pieces of work to explore transitions at different points in people's lives and a journey through many different worlds. (vignette based on fieldnotes)

This chapter will discuss the data collection and analysis process. While the previous chapter provided an overview of the theoretical work that informed my PhD, this chapter will describe how I undertook my research. I reflect on some of the challenges and obstacles I encountered and how drawing on different research approaches helped me to respond to those challenges. For reasons of clarity and coherence my three studies will be discussed concurrently throughout this chapter, but as described in the introduction chapter and the included flowchart (see p. 6) in reality the three studies proceeded each other.

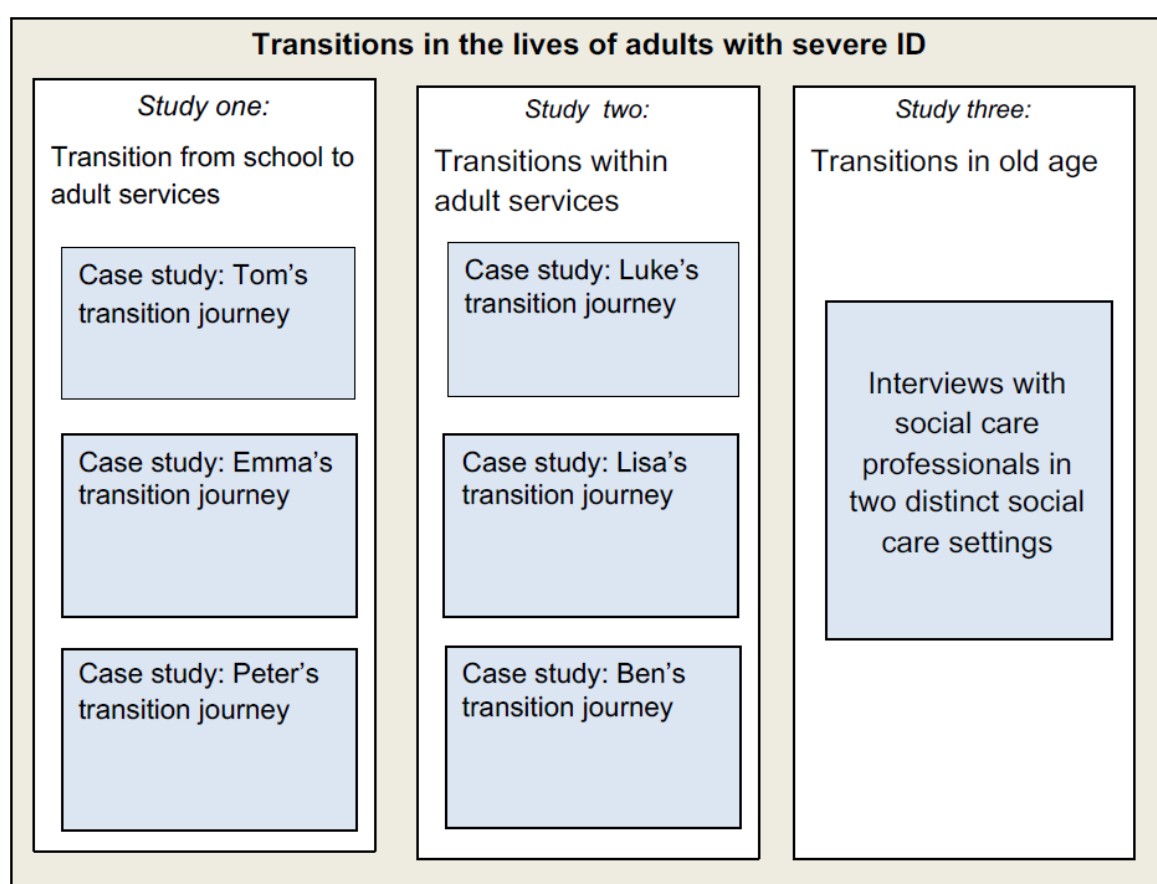
Ethics are at the heart of this study in many ways. Due to the sensitivity of the topic and the complexity of my research design, I was aware that I needed to be awake to ethics throughout my involvement with participants and my engagement with my data. I will reflect on ethical considerations and discuss my choices, actions and experiences throughout this chapter, contrasting my preparations and plans with what happened during the research process. Following an ethics of care perspective, I hope I am able to show that my research was based on being respectful, attentive and caring (Mietola

et al., 2017, Rogers, 2016). A separate ethics section is included towards the end to think more carefully about ethical key issues.

5.1 Research process - combining three studies

Taking a life-course perspective, I explored transitions in three different contexts: transitions from school to adult services, transitions within adult services and transitions in old age (table 1).

Table 1: Overview of three studies



The first two studies were based on what Yin (2003) calls an embedded multiple-case design and included three cases each. Each case referred to the transition journey of one particular young person or adult. An embedded case study design refers to the use of multiple units of analysis (Yin, 2003). In each case information was collected through different data sources and through the perspectives of different stakeholders involved in the transition and in the life of the person to explore different ecological levels of the transition process. Each case was examined before similarities and

differences were explored across cases and contexts. An in-depth examination of each single case makes the phenomena of interest tangible and grounds it in concrete events (Miles and Huberman, 1994). Exploring similarities and differences across cases later on allows researchers to move towards themes and develop a theoretical understanding of the phenomena of interest. Multiple case study designs suit studies that are informed by theory, in this case Bronfenbrenner's (1979) ecological theory. Additionally, multiple case studies generate more varied data than single case studies and therefore allow for a more comprehensive application of the theoretical framework to the data (Crowe et al., 2011, Yin, 2003).

The third study of my PhD differed from the other two. The idea to develop a third study to explore transitions in old age developed during my analysis of study one and I started to feel more and more convinced of its value during the data collection process of study two. I was keen to further explore one of the central questions parents kept asking: 'Will adult services be able to offer a place of belonging to my child? Can I trust professionals to take on the responsibility to care for my child when I am no longer here?' When I turned to the literature it transpired that there was lack of research on older age, particularly for people with severe ID (Grant et al., 2010). Initially, I explored the possibility to explore transitions in old age through case studies, mirroring the design of study one and two. I had been in contact with social care professionals and researchers with experience of conducting studies involving older people with ID, to talk about the feasibility of conducting case studies. I was advised that it was likely to be difficult to obtain consent. Often there is no guardianship agreement in place for older generations of people with ID and as parents might have passed away it would have been difficult for me to obtain proxy-consent to include people in my study. Additionally, I encountered difficulties in the initial phase of making contact with services that had experience of supporting this particular population. Thus, I decided to adopt a different design for study three, and to view it as an initial exploration of this stage of life through interviews with social care professionals only. Thus, study three did not utilise multiple data sources and did not draw on multiple perspectives. Furthermore, I was unable to involve people with severe ID themselves in the research process. Yet, study three helped to highlight the life-course perspective of my PhD and themes that emerged connected to some of the questions that had been raised by the first two studies.

While each of my three studies can stand on their own, they are all connected through a life-course perspective, an ecological understanding of transitions and a focus on people's relationships and how those influence transitions and can facilitate people's involvement. Additionally, all three studies explore the particular context participants find themselves in. Thus, findings across the three studies are context-dependent and cannot be generalised (Vavrus and Bartlett, 2006). This is particularly the case in the third study, which was conducted in two unique social care settings. Both settings were life-sharing communities, where most of the staff and people they supported lived together. Therefore, both settings are not representative of the majority of social care services and my findings differed from the general literature on transitions in old age. However, the aim of my PhD was never to generalise. Instead, by focusing on a particular context I hoped to be able to illustrate interactions between wider levels and people's lives through a concrete example and to theorise relationships between structures and individual actions (Broadfoot, 1999). I believe that an examination of particular cases can help us to understand why transitions are different for different people and how interactions between specific contexts and wider structures influence the lives of people (Flyvbjerg, 2006, Maxwell, 2012).

5.2 Research aims and questions

My PhD aims to explore transitions, firstly as processes that are inherently linked to people's past and future, secondly to explore how transitions are influenced by processes that span across different ecological levels, and thirdly, to involve the person with severe ID in the research process. Thus, I aim to explore the complexity that is involved in transitions and to understand transitions as processes that involve and impact on different people. I aim to explore transitions not from one single perspective, but to incorporate multiple perspectives including the views of families and professionals. I hope to examine how people work together to support transitions and to better understand what influences their actions during the process.

As can be seen in table 8, research questions in all three studies were developed with an ecological framework in mind. An exploration of the involvement of people with severe ID within decision-making processes remained a central aim in all studies.

Table 8: Research questions across ecological levels in study one, two and three

System	Research questions
Person with severe ID	How does the person's life look like (before and after the transition)? What kind of relationships does the person have? How does the person express himself/herself and interact with his/her environment?
Microsystems	How do different people in the person's life support him/her and facilitate involvement? How do different people in the person's life view/experience the transition process? How are people themselves involved in the decision-making processes?
Mesosystem	How do people work together?
Exosystem	What informs people's decisions (local context)?
Macrosystem	What influences people's decision-making within the wider socio-economic context?
Chronosystem	What came BEFORE, what happens NOW, what will happen THEN?

5.3 Recruitment

Recruitment for the three studies took place in Scotland. As discussed previously, my PhD did not aim to generalise or for participants and cases to be representative. Case studies, as well as life study research, are context-dependent and idiographic. They are interested in the exploration of particular contexts and processes (Plummer, 1995, Vavrus and Bartlett, 2006). Drawing on life story research helped me to recognise that it was not important to find cases or settings that were typical or representative and neither was it for me to judge if the experience of particular families or social care professionals was worth more than that of others. I was interested to recruit cases and participants with different experiences and to explore how their specific circumstances influenced transitions (Plummer, 1995).

The recruitment process was guided by combining strategies from purposive sampling and life story research. Palys (2008) defines purposive sampling as '*synonymous with qualitative research, with selection based on what you want to accomplish and what you want to know*' (p. 697). In case studies purposive sampling often occurs at two levels, firstly, selecting the cases, and secondly, selecting different units of observation to explore different aspects of the case (within-case recruitment) (Yin, 2003). In the first two studies this involved firstly finding a family who was experiencing or had recently experienced the specified transition. Secondly, it involved recruiting family members and professionals who would be able to share their experiences and views about the transition process with me and to gain access to case-specific documents. The defining questions for inclusion in the research was (i) access to relevant information and (ii) for the research not to cause any harm. I asked recruitment organisations to consider if they believed that identified families would be comfortable to meet with me several times and to allow me to speak with professionals involved in their child's transition, as well as considering if involvement in the research could pose any risks or cause any harm. Thus, I made use of the knowledge and relationships that recruitment organisations had to families (study one and two) and to colleagues (study three) to identify possible cases and participants.

5.3.1 Inclusion and exclusion criteria

In study one and two I attempted to identify cases of (i) young people or adults with severe ID whose life was currently or had been affected previously by the transition under study; (ii) parents and guardians of the person with severe ID, (iii) professionals and (iv) significant others who were involved in the decision-making process. I knew from practice and my literature review that individual transition processes vary and do not always follow processes outlined as recommended by policies. Therefore, the transition period was not specified beforehand to be able to realistically respond to individual cases and situations. Study three on the other hand aimed to explore transition practices and views of social care professionals, which required the identification of a relevant setting and recruitment of professionals within the setting. The inclusion and exclusion criteria for each study can be seen below.

Table 9: Inclusion criteria in study one

Participants	Inclusion and exclusion criteria
Young person with severe or profound ID	Inclusion criteria: • Aged between 16 and 25 • Affected by current or recent transition from school to adult services (up to two years) • Consent given by guardian/parents Exclusion criteria: • Concerns about possible harm or intrusiveness • No consent to participate from guardians/parents and at least one professional.
Parents and guardians	Inclusion criteria: • Fluent in English • Giving consent to interviews and to talk about the process (including experience of collaborative practice and documents)
Professionals and significant others	• Fluent in English • Aged over 16 years • Giving consent to interviews

Table 10: Inclusion criteria in study two

Participants	Inclusion and exclusion criteria
Adult with severe or profound ID	Inclusion criteria: • Aged between 21 and 40 (the age range was chosen in conversation with the recruitment organisations based on their experience of supporting transitions such as moving between services or moving out of the family home) • Affected by current or past transitions within adult services • Consent given by guardian/parents Exclusion criteria: • Concerns about possible harm or intrusiveness • No consent to participate from guardians/parents and at least one professional.
Parents and guardians	• Fluent in English • Giving consent to interviews and to talk about the process (including experience of collaborative practice and documents)
Professionals and significant others	• Fluent in English • Giving consent to interviews • Aged over 16 years

Table 11: Inclusion criteria in study three

Participants	Inclusion and exclusion criteria
Social care professionals within chosen social care setting	Inclusion criteria • Professionals that support adults with intellectual disabilities. • Experience of supporting people in old age*. • Experience of supporting people with severe communication difficulties, who are deemed to lack capacity**. • Participants might be support workers, team leaders or managers. Exclusion criteria: • No experience of supporting people in old age. * This study did not specify an age at which people are deemed 'old'. It was left open for participants to define what old age means to them and how they conceptualise old age as a life stage. ** Severe ID was described as people with severe communication difficulties and little verbal communication, who have extensive support needs

5.3.2 Recruitment process

Organisations were identified who had relevant experience of supporting families or adults with severe ID within the specific focus of each study. In the first two studies

two recruitment organisations were chosen for each study to try and recruit participants from different local authorities to explore the influences of different geographic regions (e.g. rural or urban), as well as the impact of different local authority policies and practices. Contact with families was made through schools in study one, and one adult service and one third sector support organisation in study two. As contact was made through organisations that were involved in the lives of families, it was anticipated that professionals working for the organisations were likely to consent to take part in the research as well.

For the third study I approached different organisations, including adult services for people with ID and nursing homes or palliative care units that advertised spaces for people with ID. Most organisations did not reply and others indicated that they currently did not support anyone with ID (nursing and palliative homes) or that they currently did not support older people (adult services for people with ID). In the end I was able to establish contact with two distinct social care settings. They were unique in their set-up as they offered shared living placements within a therapeutic community setting. Both settings explained that they had experiences of supporting people in old age and both settings described that transitions into old age were becoming more frequent for them as they had an aging population.

Details of each recruitment organisation, the number of families/participants approached by each setting and the numbers of those included in each study can be found below. I had contact with senior professionals in each organisation to go through the study's research protocol and clarify inclusion criteria. Organisations considered their involvement in the study through their internal processes before recruitment was started. Organisations sent out Participant Information Sheets, which included details about the study, my details and return slips. Flowcharts that describe the recruitment process and examples of Participant Information Sheets and consent forms can be found in the appendices.

Table 12: Recruitment process

Recruitment organisations	Criteria given to organisations	Response rate
Study 1: Special school for children and young people with additional support needs Residential school for children and young people with additional support needs	Young person with severe or profound ID aged between 16 and 25 Family affected by current or recent transition from school to adult services (up to two years) No concerns about possible harm or distress caused by research involvement There is/has been activity: families and professionals (at least one) are involved in the transition process and are interacting	3 families approached, 2 returned and 2 included Over 8 families approached, 4* returned and 1 included (*3 families decided not to take part after an initial conversation)
Study 2: Third sector organisation providing support for parents of children with profound intellectual disabilities Third sector adult day service providing placements for young adults with intellectual disabilities	Adult with severe or profound ID aged between 21 and 40 Family affected by current or past transitions within adult services such as moving out of the family home, moving between services, cases where a transition is wanted but there is nowhere to transition to, placement breakdowns No concerns about possible harm or distress caused by research involvement	Over 5 families approached, 2 returned and 2 included 3 families approached, 1 returned and 1 included

	There is/has been activity: families and professionals (at least one) are involved in transition process and are interacting	
Study 3: Community, which supports adults with intellectual disabilities within a life-sharing setting and offers supported and shared living placements. (rural area) Community, which supports adults with intellectual disabilities within a life-sharing setting and offers supported and shared living placements. (urban area)	Social care professionals that have experience of supporting people with intellectual disabilities and severe communication difficulties in old age.	3 staff members approached and 3 included. 5 staff members approached and 5 included.

Drawing on life story research, I decided that it was not for me to judge if the experiences of some families would be more interesting or valuable than that of others (Plummer, 1994). Thus, in study one and two I decided that it would be important for recruitment organisations to only contact two to three families initially, to avoid more families agreeing to take part than I was going to be able to include. I talked this through with the recruitment organisations and we decided to contact families that were in the midst of transition experiences in the first instance. This worked well for contact made with families through the first recruitment organisation in study one, but few families that were in the process of transition responded through the other recruitment organisations. The other three recruitment organisations reflected that families that were in the midst of transition might have less time to take part in a research study. Subsequently the decision was made to also approach families that had experienced transitions in the past.

In the first study six families got back to me. The two families that responded through the first recruitment organisation were both in the process of planning the transition from school to adult services. This was the same for three families that responded through the second organisation, but after initial phone conversations all three families decided not to take part. One mother, after some contemplation, decided that she was not ready to talk about her experience. Their transition had been in a crisis for a while and she felt not well enough to speak about her experience. One family decided not to take part as they felt they could not commit their time to the study. The young person involved in another family experienced a sudden change in health and it was felt by the school and mother that it would be better not to go ahead with the study. Subsequently, information about the study was also sent to two families who had experienced the transition from school to adult services within the last two years, one family responded and was included.

In the second study recruitment was slower. None of the first two families that were approached by the first recruitment organisation responded. During a subsequent meeting the organisation suggested to contact a number of other families, including one family whose transition had been stuck for a while. Although the lack of activity meant that I was unable to recruit many participants, the recruitment organisation and I felt that it would be important to include a case which portrayed how it could be difficult for some families to move forward with the transition into supported accommodation. The second family that responded had experienced the transition into supported accommodation over fifteen years ago, but had been involved in a number of subsequent changes since. After an initial conversation with the mother I decided that the case would offer an interesting exploration of their experience of over fifteen years in adult services. Similarly, the second recruitment organisation suggested to contact one family whose son had moved into supported accommodation five years previously, but who had experienced more recent changes to his support package. Thus, the initial focus on the transition widened and I decided to also focus on subsequent changes to people's programs and funding packages.

5.3.3 Conceptualisations of severe ID

None of the studies involved an assessment to determine people's IQ levels or the extensiveness of their support needs. In first instances, recruitment organisations identified if the person was meeting the criteria for severe ID, as defined within the research protocol. During initial conversations with recruitment organisations and families, I was able to ask questions about the person (study one and two) and the people they supported (study three). In study one and two all young people and adults were described as needing constant support and supervision during the day. However, in the third study participants discussed experiences of supporting people from mild to severe ID. The term severe communication difficulties was used by participants to refer to cases where the involvement of people in decision-making processes was challenging, but not all cases referred to those with severe ID. My own terminology was challenged during interviews as participants discussed issues around capacity and involving people in other circumstances, including people who had developed dementia and people with severe mental health difficulties. All data was included in the analysis but instances where participants explicitly referred to people with severe ID or severe communication difficulties, including people who had developed dementia, were highlighted in the findings chapter.

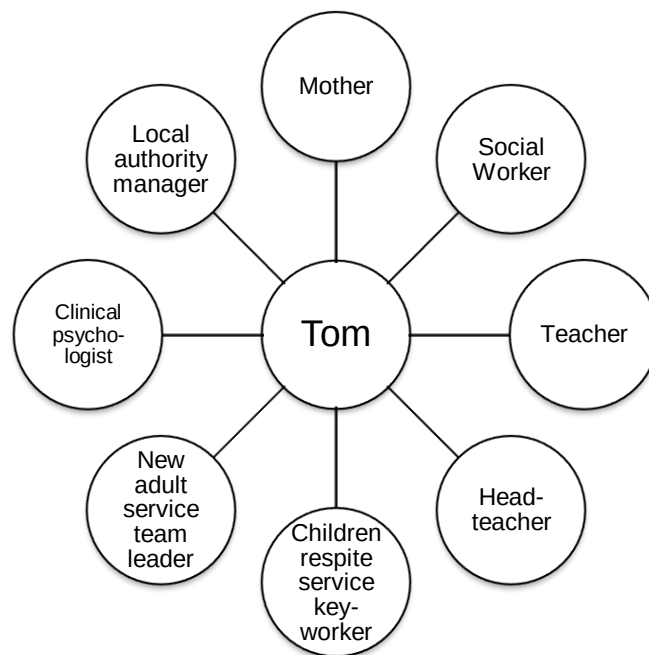
5.4 Cases and participants

The following section below will introduce the background of cases and participants in each of the studies.

5.4.1 Study one: Transition from school to adult services

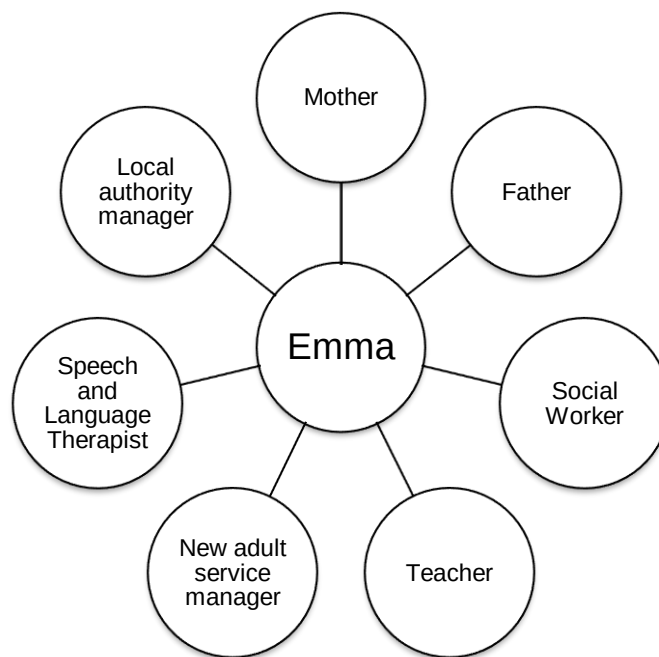
Study one explored the transition journey of three young people (three cases), who will be referred to as Tom, Emma and Peter (pseudonyms). Tom and Emma lived in the same local authority and went to the same school. Peter's family lived in a different local authority. An overview of each case and participants involved can be seen below. More detailed information about each participant and their contexts is presented within the findings chapter.

Case 1: Tom



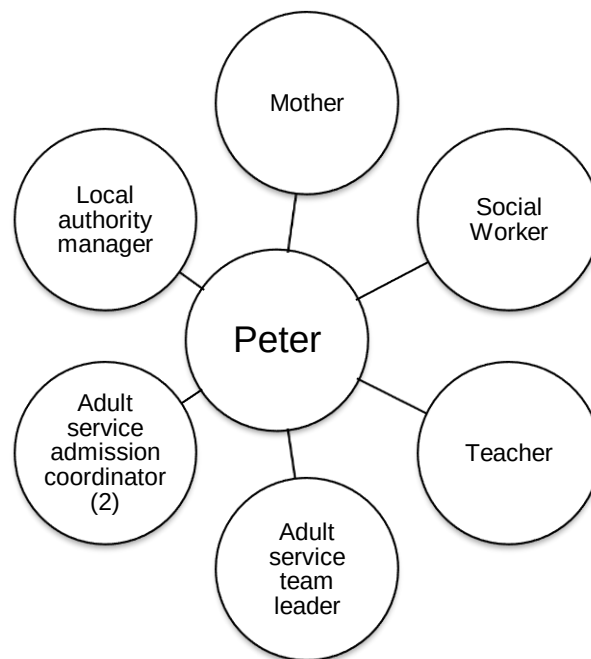
Participants	Contact
Tom was sixteen at the beginning of the study. He had two more years at school but was approaching a transition from children to adult respite services. He had a diagnosis of autism and severe ID.	One afternoon spent within his school setting. Previous contact through past work at his children respite service.
Mother	Three interviews
Social worker	One interview
Teacher and Headteacher	One joint interview
Children respite key-worker	One interview
Adult service team leader	One interview
Clinical Psychologist	One interview
Local authority manager	One interview

Case 2: Emma



Participants	Contact
Emma was seventeen at the beginning of the study and in her last year of school. She had a diagnosis of autism and severe ID.	One morning spent within her school setting. Morning and afternoon spent within her new adult day service.
Mother and Father	Two interviews with Emma's mother and one joint interview with both parents.
Social worker	Two interviews
Teacher	One interview
Adult service manager	One interview
Speech and Language Therapist	One interview
Local authority manager (same person as in Tom's case)	One interview

Case 3: Peter

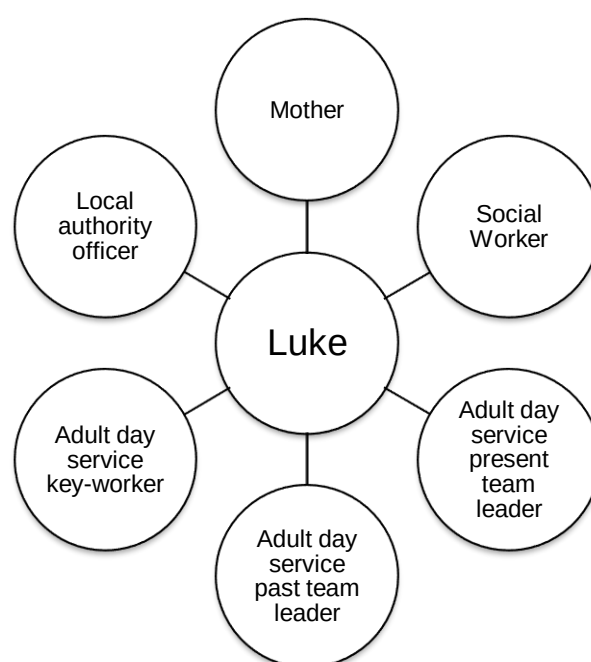


Participants	Contact
Peter was 19 at the beginning of the study. He had moved from a residential school to a residential adult service one year before the start of my research. He had a diagnosis of autism and severe ID.	Half a day spent with Peter at his residential adult service
Mother	Two interviews
Social worker	One interview
Teacher	One interview
Adult service team leader	One interview
Adult service admission coordinators (2 people)	One joint interview
Local authority manager	One interview

5.4.2 Study two: Transitions within adult services

Study two explored transition journeys of three adults (three cases), who will be referred to as Luke, Lisa and Ben (pseudonyms). Families lived in three different local authorities in Scotland. Luke lived in the same local authority as Tom and Emma. Lisa and Ben lived in different local authorities close to each other. More detailed information about each participant and their contexts is presented within the findings chapter.

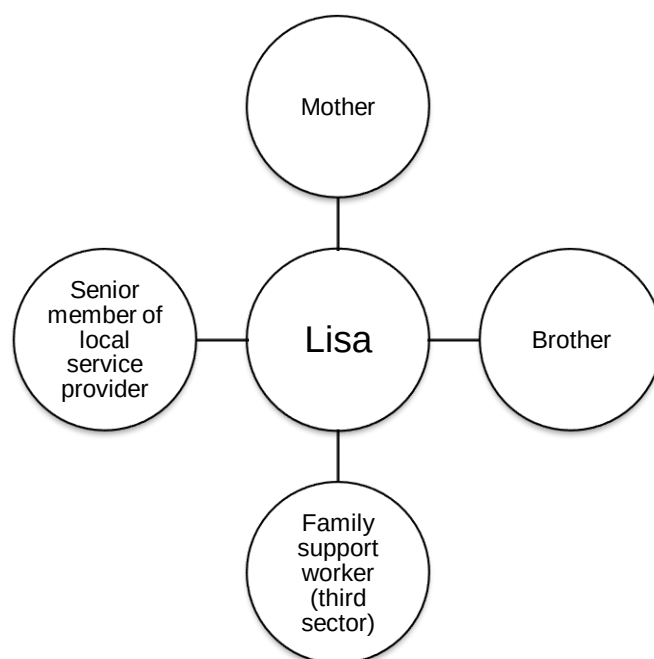
Case 1: Luke



Participants	Contact
Luke was twenty-five at the beginning of the study. He had a diagnosis of autism and severe ID. Luke moved out of his family home five years before the start of my research and was currently experiencing a review of his support package.	One afternoon and one morning spent with Luke at his adult day service.
Mother	Two interviews
Social worker	One interview

Day service past team leader	One interview
Day service present team leader	One interview
Day service key-worker	One interview
Local authority officer	One interview

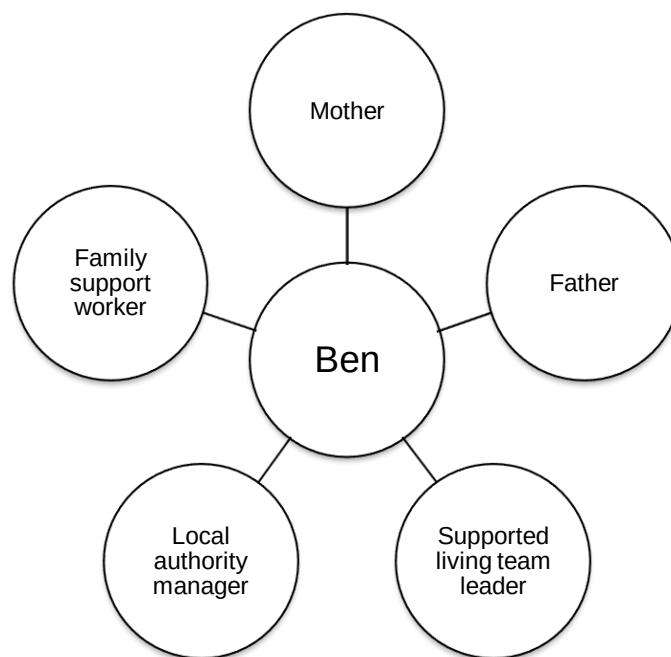
Case 2: Lisa



Participants	Contact
Lisa was twenty-eight at the start of the study. She had a diagnosis of profound and multiple learning disabilities. Lisa's family wanted her to move out of the family home. An initial meeting had taken place late 2017 but Lisa's social worker had been off sick since.	One morning spent with Lisa at her adult day service.
Mother	Two interviews
Brother	One phone interview

Family support worker through a local third sector family support organisation	One interview
Senior member of a local service provider	One interview

Case 3: Ben



Participants	Contact
Ben was thirty-nine at the beginning of the study. He had a diagnosis of severe ID and severe epilepsy. He had moved into a shared house in 2003. More recently he had experienced changes in his health and participants described an ongoing need to review his support.	Half a day spent with Ben at his house.
Mother and Father	One interview with Ben's mother and one with both his mother and father.

Supported living team leader	One interview
Local authority manager	One interview
Family support worker (same as Lisa's)	One interview

5.4.3 Study three: Transitions in old age

Study three explored the experiences of social care professionals in two distinct social care settings. Participants described both settings as life-sharing communities where people with intellectual disabilities and most of the staff live and work together. Most participants had lived and worked in their setting for over ten years, some for over twenty and thirty years. Therefore, participants had experiences of supporting adults across their life course. While the uniqueness of both settings allowed me to explore transitions in old age, it is important to highlight that the unique nature of both settings is not representative of most social care settings for adults with intellectual disability. Both settings supported adults with intellectual disability across the range from mild to severe. The number of people with severe ID was smaller and participants had fewer experiences of supporting people with severe ID but were able to reflect on a number of cases. Furthermore, questions around capacity were present in cases of people who had developed dementia. All participants had higher education qualifications in health or social care related professions.

Table 19: Participants study three

PSEUDONYMS	BACKGROUND INFORMATION
JOAN	Had lived in setting one for over thirty years. She was now involved in various role, such as support and supervision of other staff members.
BETH	Had lived in setting one for over fourteen years. She was responsible for one of the houses, where she lived with people with additional support needs.

MIA	Had lived in setting one for more than four years with a break in between. She was responsible for one of the houses, where she lived with people with additional support needs.
OLIVER	Had lived in setting two for more than fifteen years. He was part of the management group.
JACOB	Had lived in setting two for more than seven years. He was responsible for one of the houses, where he lived with people with additional support needs.
ROSIE	Had lived in setting two for over twenty years. She was involved in various roles, such as supervision and training.
SOFIE	Had lived in setting two for over twenty years. She was responsible for one of the houses, where she lived with people with additional support needs.
HELEN	Had lived in setting two for more than twenty years. She was now involved in training, recruitment and supervision.

Overall, 48 participants were recruited across the three studies.

Table 20: Participants across the three studies

Young people and adults with severe ID	6
Mothers	6
Fathers	2
Brother	1
Teachers/Headteacher	4

Health professionals	2
Social Workers	4
Local authority senior professionals	4
Social care professionals	19
Family support worker (third sector)	1

5.5 Reflection on the within-case recruitment process in study one and two

The recruitment process in the first two studies was more complex than in study three, as I attempted to use different data sources and to recruit people from different backgrounds involved in each transition process. The following section will reflect on my experiences of recruitment in the first two studies and identify a number of challenges I encountered.

5.5.1 Recruitment of fathers and siblings

In both studies I struggled to recruit fathers and siblings. In all cases mothers contacted me and remained my main point of contact. Mothers seemed to be main carers for their children and the main point of contact with professionals. In some cases mothers felt that fathers did not need to be involved or that it might be difficult to arrange a time where both could be present and that it would be too difficult to arrange meetings with their other children as they lived too far away or mothers felt that they had had only very little involvement in decision-making processes. In the end I was only able to recruit two fathers and one brother. The centrality of mothers stood out in this research and thus it joins the large number of studies that have described the fundamental role of mothers in the lives of their disabled children over past decades (Adams and Jahoda, 2019, Hubert, 2011, Knight, 2013, Wilkinson, 1996). In order to not disregard my interviews with fathers and one brother the term ‘family’ was used within the findings chapter in relation to themes that were present in all interviews with family members, ‘parents’ was used where findings did not relate to the interview with the brother and ‘mothers’ was used in instances where themes only related to interviews with mothers to highlight their special involvement in the lives of their children.

5.5.2 Recruitment of professionals

During first meetings with mothers, mothers were asked to identify professionals who were or had been involved in the transition process. Additionally, when possible, I used review-meeting notes to identify key professionals. In the first study all professionals who were approached responded. I was particularly surprised at the ease of getting social workers involved. I assume that recruitment was easier in the first study because parents and professionals had a close involvement at the time and talked to each other about the study.

In the second study it was more difficult to recruit professionals. In Lisa's case there had been no meetings for a while as her social worker was off sick. In Luke and Ben's case the transition into supported accommodation had happened quite a few years ago and contact details of a number of professionals who had been involved at the time were not available. Where I had contact details it was difficult to arrange interviews with social workers and adult service professionals. Although a number of professionals in study two had first expressed an interest to take part, they later stopped responding to me. As my follow-up calls and emails remained unanswered, I found it difficult to balance my research objectives and wish to speak to as many as people as possible, with people's rights to not take part. I decided to not attempt to make contact more than two times. It felt very frustrating at times when scheduled interviews were cancelled last minute or phone calls not returned. In my fieldnotes I wrote:

My own difficulties to get in touch with social workers and adult service professionals seems to mirror some of the difficulties mothers speak about in interviews when their emails and phone calls remain unanswered and they do not know what is happening. If I already feel stressed and frustrated now, how strong must the feelings be for mothers, when for them it is about financial worries and the welfare of their children and support for themselves? (fieldnote, study two, August 2019)

5.5.3 Involvement of local authority senior professionals

I decided to try and interview professionals with strategic and commissioning responsibilities within the different local authorities to deepen my understanding of the policies that were informing the actions of professionals. In discussion with my supervisors, we decided that the interviews with local authority seniors would not be

case specific and for reasons of anonymity, no reference was made to neither names of the families, nor professionals involved in their transitions. Instead, the interview guide was followed more broadly referring to general cases (see appendices).

5.5.4 Proactive families – recruitment bias

The residential school in project one reflected that they had sent out letters to a number of families who were experiencing difficult transitions. Many of the young people at the school were described as having challenging behaviour and many required complex care packages. As I had worked at the organisation previously, I had been very interested to include cases with high complexity, but none of the families came forward. Similarly, other recruitment organisations felt that due to high levels of difficult emotions and hardship families might not have felt able to participate in the research study. This leads to some bias in this study as I recruited parents, who were all proactive and where the transition, although experienced as stressful, seemed to move towards relatively positive outcomes. The two studies demonstrate the challenges for researchers to access views of parents who experience greater levels of conflict and who might feel less able to take on strong advocacy roles.

5.6 Data collection

The analysis section is presented separately from the data collection process to give clarity to the writing but, as it is typical within case study research, analysis and data collection overlapped and informed each other (Miles and Huberman, 1994). Particularly, the last two sub-points will reflect on processes that involved both collecting data and taking first steps into the analysis.

5.6.1 Data sources

The use of different data sources during data collection and analysis makes case study research attractive when the focus of the study is on process and interconnections (Miles and Huberman, 1994, Yin, 2003). Researchers are able to follow converging paths of inquiry and look at the phenomena from different angles (Yin, 2003, VanWynsberghe and Khan, 2007).

In the first two studies I used some of the most common data sources used in case study research: (1) individual interviews, (2) observations and (3) case specific and general documents (Yin, 2003). Using different data sources helped me to explore different research questions and ecological levels. Links between the data sources and research questions can be seen in the table below. The third study used individual interviews and group interviews only.

Table 21: Data sources – Research questions in study one and two

Data sources	Research question
Observations	What is the researcher's impression of the person? How does the person express herself/himself within the world? How does the person relate to others?
Interviews	How do people describe the person? What is their relationship to the person? How are decisions made? How do people work together? What needs, supports or barriers to the transition process are highlighted? What informs decisions? What influences decisions? What happens Now and Then and In-between?
Specific Documents (Reports and plans about the person and the transition process)	How is the person described? Which support networks are identified? What needs, supports or barriers to the transition are highlighted? What informs the decision (frameworks, assessments, guidelines)? How is the transition process described, outlined? What happens/happened when and who is/was involved? (meetings, decisions, events)
General Documents	What influences the decision? (resources, values, guidelines)

(Strategic plans and government agenda, legislation and policies, budget plans)	How should transition processes ideally look like?

During all studies, I kept a fieldnote diary and the use of fieldnotes was key to the data collection and analysis process.

5.6.1.1 Interviews

I still get nervous before each interview and I often feel incredibly tired afterwards. It has gotten better and my questions are now more open, giving more space to participants to take the interview to areas that I did not anticipate. But I still always listen back and regret not having noticed a certain comment and asked further or not left a pause for long enough. So many missed opportunities. I am very happy that I decided to do multiple interviews with parents to be able to follow transitions as processes because it gives me the opportunity to go back and clarify and ask more. Speaking to people more than once gives my data a different depth. (fieldnote, study one, August 2018)

Semi-structured interviews were used to give participants space to highlight topics and issues of their own concern, while a structure of guiding questions allowed for the research to be grounded within the ecological framework (Miles and Huberman, 1994). I started by asking questions about the person with severe ID, their way of expressing themselves, relationships to others, routines, likes and interests. This was followed by exploring the role of each participant in the life of the person with severe ID, as well as their role in the transition process. Later questions focussed on collaborative practice, limitations and facilitators within the organisational realm, and lastly, reflecting a life-course perspective, I asked participants about their thoughts and hopes for the future. Examples of the interview guides can be found in the appendices.

Within each study the same interview schedule was used with all participants with some differences between interviews with family members and professionals in study one and two. Additionally, in study one and two the interview guide was complemented in subsequent interviews to include new information that I had learned about during the data collection process. For example, if mothers identified one particular meeting as central to the decision-making process, I subsequently explored this meeting with other participants who had been present. Thus, interviews in study one and two

became more case-specific the more knowledge I had about each case. Additionally, being able to speak to mothers more than once in the first two studies, and having both group and individual interviews in the third study, allowed me to check my own interpretations and assumptions with participants directly.

Interviews were recorded on an encrypted recorder and transferred to an encrypted laptop. Both the laptop and recorder were stored within a locked suitcase when held at home, or within a locked cabinet at University premises (see appendix).

5.6.1.2 Group interviews

In study three data was collected in the form of individual interviews and group discussions. Within qualitative research individual interviews are the most commonly used data collection strategy (Lambert and Loiselle, 2008, Nunkoosing, 2005). Group discussions offer an alternative to individual interviews, as they provide data that is more interactive by facilitating discussion among participants. Group discussions are able to complement individual interviews by giving space to participants to comment on each others' experience, to agree and disagree (Lambert and Loiselle, 2008). Thus, the spectrum of perspectives is highlighted and participants are able to respond to each other (Duggleby, 2005, Freeman, 2006). The combination of both individual interviews and group discussions has been highlighted as an advantage to offer richer and more nuanced data (Gill et al., 2008, Kaplowitz and Hoehn, 2001, Lambert and Loiselle, 2008). While group discussions provide space to examine and explore different or similar opinions and views, individual interviews give space to listen to individual experiences. Furthermore, during group discussions I was able to focus more on external influences, the set-up of both settings and collaborative practice, while individual interviews gave space for people to share their individual experiences and emotions. Seeing participants more than once allowed me to clarify and further explore themes of interest. The groups included all social care professionals in each setting who had also agreed to meet with me for individual interviews. Thus, the group discussion in setting one consisted of three people and myself and five people and myself in setting two.

I transcribed all fifty-two individual interviews across study one, two and three and the two group discussions in study three myself verbatim. Drawing on narrative profiles

(Seidman, 2006), each participant received a summary of their interview, as well as findings of the study as a whole (see appendices for examples). This proved very valuable and three participants asked to have certain passages from the interviews changed to clarify what they had wanted to say or to add additional information.

5.6.1.3 Specific documents

I find myself sitting in offices at the schools and adult services with big folders in front of me. Looking through personal plans, social work assessments and review meeting notes (some with a lot of detail, some with only a few bullet points that don't tell me much, and some notes that should be there but cannot be found). They help me to understand what professionals focus on, what is important for them in making decisions (all of them seem to have a strong focus on risks and needs). Would it have been enough to just read them? Did I need to meet Tom, Emma, Peter, Luke, Lisa and Ben? Yes, because it made everything more real. I am not quite sure how to describe it, but in a way it made my research three-dimensional. It would have never been enough to only read and speak about each person. (vignette based on fieldnotes)

Specific documents were documents that held relevant information about the person with severe ID and the transition process. Those included Individual Education Plans (IEP), personal plans, assessments, meeting notes and letters. Documents were third party documents and there were restrictions placed on me about how and where I could access them. To use specific documents, permission needed to be obtained from the original authors and/or organisations. If permission was declined or I was unable to obtain permission, the documents were not used for analysis, but the content of documents was at times discussed within interviews. In the first study all relevant authors and organisations did give consent and I had access to IEPs, personal plans, review meeting notes and social work assessments. In the second study it was more difficult to get access to documents as I was only able to recruit the social worker in Luke's case. In Luke's case I had access to his Personal Plans, Risk assessments and meeting notes. I was able to speak with his mother and social worker about his current social work assessment but I was unable to obtain it. In Lisa and Ben's case I was able to read their personal plans and risk assessments through their adult services during my visit and in Lisa's case this also included recent meeting notes about her transition. I was unable to obtain social work documents.

5.6.1.4 General documents

General documents used in the study were public documents that held information

about legislative and strategic influences to the transition process. Those included strategic plans in the different local authorities in relation to adult service provision and budget plans. Those are accessible to the public and I had access to them through local authority and government archives. All professionals referred to the national learning disability strategy 'Keys to life' as informing their work. Additionally, professionals made references to more specific policies or documents that reflected changes in the planning of service provision in the local area. This included a shift towards single tenancies and core and cluster provision in a number of local authorities and a recent change in one local authorities' transport policy, promoting for people with ID to use (if possible) public transport instead of receiving funding for taxis. Finding such specific policies was more difficult and I spent many hours looking through pages and pages of local authority budget and strategic plans and I submitted a freedom of information request to help me clarify some of the information. Working with general documents highlighted to me the tension between documents that described ideals of practice and those that documented a decrease in resources in local areas.

5.6.1.5 Observations

Why am I doing observations? Are 'observations' the right word? What am I doing when visiting each person and spending time in their company? I can feel how valuable it is. I am convinced of its importance but how do I explain why and how do my observations connect to the rest of my data? (fieldnote, study one, May 2018)

In study one and two I had direct involvement with people with severe ID through observations. Most observation studies in the context of intellectual disabilities occur in naturalistic settings and combine observations with interviews of significant others (Mietola et al., 2017, Oulton et al., 2018, Simmons and Watson, 2014). In studies that involve people with severe ID, observations are usually used to conduct a detailed analysis of behaviour and communication. Yet, Simmons and Watson (2014) and Mietola et al. (2017) describe how observations can also be used to emphasize human and emotive interactions and to gain an understanding of the person and their lives. Observations fall into two categories: participatory and non-participatory. Researchers caution that it is important to be aware of the ethical implications of engaging directly with someone who has profound and complex needs, and to avoid causing distress by becoming another face that drifts in and out of the person's life without him/her

having any control over it (Nind, 2008). During transitions, people often experience frequent changes in staff and an increase in professional involvement. Becoming another new and unknown person, without being able to offer a consistent relationship initially lead to the rejection of participatory observations as a method in this study. However, it became clear that it was difficult to stay an outside observer during data collection as I found myself in schools or at people's day services or homes, where interactions happen naturally. During visits it felt important to introduce myself to each person, often staff would start to engage me in activities and during each observation there were moments where the person started to interact with me out of their own initiative. I felt that it was important to respond to people and recognize their agency in choosing to interact with me. In the end my observations can be described as a mix between participatory and non-participatory observations. Participation was not structured or initiated by me but I followed the person and their setting as naturally as possible. Particularly in study two, where all my visits included me spending time with the person and only one member of staff, I was asked to join activities such as having lunch together, going for walks or doing crafts.

We have just finished lunch. 'What is her name?' Eva asks Ben and points at me. He turns to look at me. We look at each other. He looks back at Eva. 'Pa' he says, 'Paula' Eva says slowly pronouncing it phonetically. 'Pal' he says looks at me and smiles. 'Yes Paula' I say. (...) After lunch I help to tidy up. I feel very relaxed in this environment. It feels familiar. I miss it. Ben says 'car'. Eva asks 'what colour is your car?' He looks at her and says 'car'. Eva says 'It is red' and she signs 'red' in Makaton. He copies and smiles. 'You are good at signing Ben. You have a red car' I say using Makaton signs for red and car. 'Car', he signs and smiles. Then we get ready to go to the car. Before we go out Ben reaches out and takes my hand. He pulls me towards him, he squeezes my hand tightly, moves his face closer to mine, gives me a big smile and says 'car'. (vignette based on observation, study two, August 2019)

Many studies do not provide details on the structure and methods used during their observations. However, Simmons and Watson (2014) used vignettes successfully in their research with a young man with profound and multiple learning disabilities. Vignettes involve writing in great depth about small events. The use of rich and descriptive vignettes related well to my focus on thick descriptions and narrative within the data collection and analysis of each case inspired by case studies, ethnography, life story research and narrative profiles. In the vignettes I noted down my observations of people interacting with their environments and also reflected on my experience of

doing the observations. Sometimes I was able to write vignettes while in the setting if it was a group setting and I was sitting on the edge as an outside observer, and sometimes I needed to record my observations after the visit or during short breaks in activities.

While I thought about how to best conduct the observations, I also needed to consider carefully how I was going to use my observations and represent the six adults. During the hours that I spent with each person I noted down pages and pages of observations and reflections. Going back to the aims of my study and drawing on ethics of care helped me when it came to choosing which material to include and how to include it. Following an ethics of care perspective, the aim of my study was not to explore **if** people with severe ID can be involved or **if** people have views, but to examine **how** they are involved and if their preferences are taken into consideration during transitions. When making choices about which vignettes to include, it was important to me to show the six adults as people with interests, who are valued members of families and communities. Thus, I decided to include vignettes that portrayed people as interacting, communicating and engaged in activities. Correspondingly, while conducting the observations I recognized the importance to emphasise that the observations were based on interactions between myself and each person. I felt that vignettes that would solely offer descriptions of the person, without references to my own experiences, were in danger of framing the observations within a 'subject' and 'object' structure, creating a picture of myself as the expert researcher, observing each person as an 'object'. Thus, I decided to include reflections of how I experienced meeting each person within the vignettes to stress the impact each person had on me and to emphasise the agency each person had in shaping our interactions.

As I have discussed in the introduction, I wanted to include observations not to 'give voice', but to make the lives of people with severe ID more visible. I am not claiming that through my observations I was able to represent the views of the young people and adults. My vignettes are fractional, situational and based on my own experiences (Mietola et al., 2017). Yet, as Young (1997) and Mietola et al. (2017) write, direct experiences and engagement with people helps researchers to get a better understanding of their everyday lives and the possibilities available to them within their immediate environments.

5.6.1.6 Fieldnotes

I used my fieldnotes in two ways (i) to record new information that informed next steps within my data collection and (ii) to reflect on my own experiences and thoughts. I used Miles and Huberman's (1994) contact summary forms to document information I received about meetings, events, conversations or documents that seemed to be relevant to each transition process and I also used the forms to identify areas of interest that I wanted to know more about and highlight information that I needed to follow up with other stakeholders (see appendices for examples).

Next to the contact summary form I used a reflective diary. My reflective accounts had a looser structure and were more personal, offering me space to freely write down my thoughts and feelings. The reflective notes helped me to remain aware of my immediate interpretations and inferences and to record themes and questions that started to come up for me. The reflective accounts were helpful during the analysis to keep alive my experiences of the research encounter and to practice reflexivity. In ethnography reflexivity helps to make transparent the relationship between the researcher and the field (Eriksson et al., 2012). Instead of seeing my reflective accounts as biases and unwanted parts of the analysis that I needed to remove from the research process, I used them to make visible my own voice and position within the research process (Stenhouse, 2009).

5.6.2 Data collection timelines

The data collection process for each case is visualised in the following timelines. In study one and two the data collection process for each case started with the interview of mothers. Mothers preferred to combine our first meeting to talk about the study and to give consent with their first interview. Additionally, it felt important to meet with mothers first to be able to explore the best way to meet their children and conduct the observations. Meeting with mothers first allowed me to ask if mothers had any concerns about the observations. I would have liked to meet the six adults shortly after the first interview, as they were the people at the centre of the process. However, I relied on the availability of schools and adult services to facilitate the observations, as well as the availability of professionals to conduct the interviews. Particularly social workers had busy schedules and in Tom and Emma's case I met with social workers before conducting the observations, while my observations were delayed in Peter and

Lisa's case. Similarly, I had planned to end the data collection process with a last interview with parents, but due to difficulties to arrange and rearrange interviews with local authority managers, as well as a number of adult service professionals, I spoke to a number of professionals after my last interview with parents in Luke and Ben's case.

In some cases the transition had taken place in the past, and as participants could not always remember, the data collection required a closer checking back in with participants and clarifying when events had taken place and who had been involved.

Figure 4: Data collection timeline -
Tom's case study one

May 2017	First interview mother Interview teacher and headteacher and document collection Interview social worker and document collection Observation at school
June 2017	Interview respite key-worker and document collection Transition to adult service
July 2017	Second interview mother Interview adult service
August 2017	Interview LA social care manager Interview Clinical Psychologist
September 2017	Third and last interview mother

Figure 5: Data collection
 timeline – Emma’s case study
 one



Figure 6: Data collection timeline
– Peter's case study one



Figure 7: Data collection timeline
– Luke's case study two

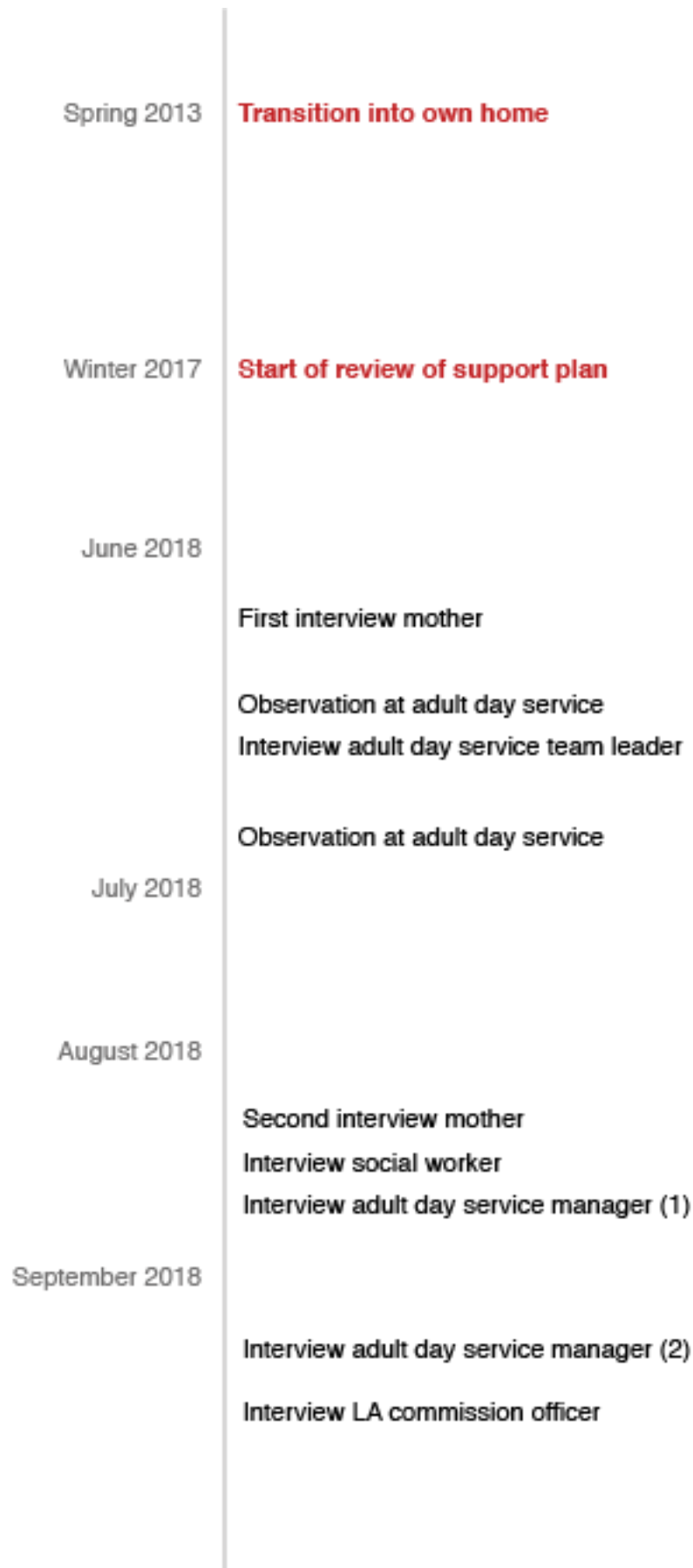


Figure 8: Data collection
timeline – Lisa’s case study
two



Figure 9: Data collection
timeline – Ben's case study
two



Figure 10: Timeline data collection study 3



5.6.3 Using visual displays: timelines and proximity displays

Visual displays are commonly used in case studies to help researchers make sense of their data. They often include displays that help to visualise processes over time or displays that illustrate relationships between characters or systems (Miles and Huberman, 1994). During the data collection process of study one and two I started to create timelines to record the information I received about each transition process and I created proximity displays to visualise the involvement of people in the transition process. Displays are described as an important step within case study analysis, but they are often created by the researcher. I decided to involve participants in creating them. Introducing a visual representation of the transition during interviews helped me to validate my interpretation of the process with participants, but it also changed the dynamic of the interview. Bagnoli (2009) writes how the use of visual methods in interviews helps researchers to access different levels of experience. The visual display is able to fulfil two functions, firstly to incite a different way of thinking about and seeing the phenomena under investigation, and secondly it becomes a record of the interview that has been validated by participants (Varga - Atkins and O'Brien, 2009). I will discuss my use of timelines and proximity displays in more depth in the analysis section.

5.6.4 Triangulation of data sources

The triangulation of different data sources in case study research is conceptualised differently by different authors. For example, Yin (2003) defines it as adding to the validity of case studies, as different methods are thought to verify the same results. However, other authors describe how different data sources add different perspectives to understand each case (Merriam, 1998, Maxwell, 2012). My understanding of triangulation conforms with the latter view. Every interview, observation and reading of case specific and general documents gave new clues and added new pieces to my understanding of the transition. For example, interviews offered subjective accounts in which participants reflected on their experience of certain events, while documents offered evidence on when the events took place and who was there. Using different data sources helped me to get different kinds of information. Moreover, documents and observations were able to enrich the interviews. Looking at assessment or review meeting notes together facilitated more information than simply asking: 'Can you tell

me about the review meeting?’ Being able to clarify last pieces of the puzzle in second or third interviews and emails had the benefit of coming to a feeling that there was data saturation and that I had enough data to allow for a holistic understanding of the process and the roles of different stakeholders involved. Yet, this feeling of holism was not always there and in the beginning I had difficulties to see connections between data from different sources and different ecological levels. Particularly, my observations felt disconnected from my other sources of data. Only really in the end, once I had reached a sense of data saturation was I able to understand the role of my observations and the role of the person with severe ID within the transition and research process. I realised that my experience of disconnect was an important part of my findings, and I reflected on my experience of gaps across different ecological levels as part of my findings and discussion.

5.7 Ethics

As study one and two involved participants who were deemed to lack capacity to give informed consent, I was required to apply for ethical approval through the ‘NHS Scotland A Research Ethics Committee’ in two separate applications. I submitted a detailed Research Protocol, Participant Information Sheets, Consent Forms and Risk Assessments. Ethical approval was gained for study three through the University of Edinburgh. Approval letters can be found in the appendices. The ethics applications in study one and two focussed in how far involvement in the study could be of benefit to people or cause harm to participants with severe ID (next to considerations of consent, anonymity and secure data management). I needed to think carefully why I wanted to involve people with severe ID in my research and how I was going to ensure that they and other participants felt safe during the research. Once I had received approval for each study, I was aware that this was not the end of me needing to be aware of ethics. While the ethics applications helped me to prepare for ethical challenges, meeting ethics in practice was different in many ways than anticipated. I realised that ethics are context-dependent and present throughout the research process within my actions and choices made (Brannely and Boulton, 2017). Throughout the recruitment, data collection and analysis process I drew on ethics of care and its emphasis on caring practices to guide my actions, drawing on the principles of attentiveness, responsibility and responsiveness (Tronto, 1993). In the

following section I will highlight how those principles helped me to plan my research and later on navigate through a number of challenges that I encountered. I will focus on five key-ethical considerations that were central to my ethics applications and the subsequent research process. These are:

- (1) Sensitivity of topic
- (2) Anonymity and potential issues regarding care of vulnerable children or adults
- (3) Involvement of the person with disabilities and consent (study one and two)
- (4) Involvement of mothers (study one and two)
- (5) Insider research, reflexivity and transparency

For examples of my data management plans please refer to the appendices.

5.7.1 Sensitivity of topic

This research involved a sensitive topic, where specific issues, such as conflict of opinions, lack of resources, challenging behaviour, concerns over quality of care, placement breakdowns or struggles with care demand could arise. Given the nature of the topic area, there was a possibility that participants may become distressed during interviews (e.g. talking about concerns over quality of care, struggles with care demands, end of life care or death). Plans had been in place to stop interviews, only continuing if the participant felt able to do so and details of support were provided for participants before the interview started. Particularly in interviews with family members and social care professionals I needed to be attentive and closely observe how my questions affected them. This involved making space for participants to talk about concerns or situations that were important to them, being able to respond to the need of participants to 'get things off their chest' and being open to leave the interview guide and let participants take the lead. In a number of interviews, I realised that participants valued the opportunity to speak at length about difficulties they had experienced, reflecting that in the midst of providing care and trying to get on top of bureaucratic tasks, there was often little room for themselves and their own feelings. Thus, I needed to be flexible and be responsible to allow participants enough time to speak to me. I didn't want to leave them feeling like they had not been listened to by trying to squeeze interviews into fixed time frames. There was only one interview where a participant became visibly sad and needed to cry when remembering the passing of a number of people she had supported (study three). The interview was stopped shortly to allow

me to check in with her. After a cup of tea she asked to continue the interview and reflected that being sad was part of the process of remembering. After the interview I asked her again how she felt, and we spent some more time talking about her experience of taking part in the study. She said she was surprised how strong she still felt about her experiences but that it had been positive to talk about it and to remember.

5.7.2 Confidentiality and potential issues regarding care of vulnerable adults

In each study, due to the sensitive nature of the topic a risk assessment had been written beforehand to help me to be clear about my responsibilities and possible risks in relation to issues of child and adult protection. The risk assessment was used in complementation to organisation's and local authority's own policies of Child and Adult Protection and Whistle Blowing Procedures. Participants were informed that the content of discussions or interviews was confidential, but that I would need to follow up on any concerns about the welfare of young people and adults. Luckily, no concerns about the care and welfare of people were raised in any of the studies. However, the mother in one of the cases shared with me her frustration about a number of social work and social care professionals and she spoke to me about past and existing conflicts with the adult service that was supporting her child. Those related to managerial and bureaucratic processes, being unresponsive to her calls and emails, but not to the direct care of her child. Her interview raised concerns about the collaborative practice between families and professionals and as I was also going to speak to those professionals I needed to carefully think about confidentiality. After our interview I spoke to her about it and she said that she would not like the service to know about her concerns. Thus, although I attempted to portray each transition process in detail, I needed to leave out data that directly referred to people talking about each other, sharing thoughts with me that they had not shared with the person themselves. I decided to provide a general description of situations that involved high complexity without including extracts from interviews and my general write-up of her concerns was checked with the mother once data collection was completed to ensure she felt comfortable with my account.

Additionally, it was important to consider confidentiality in relation to the representation of participants and the possibility for people and organisations to be identifiable. People with severe ID comprise a small group and there is a high risk for people to be

identifiable based on descriptions of unique behaviours and needs, parents' professions or family set-ups (Jindal-Snape, 2016). When I set out to do the research I decided that I would attempt to portray each transition process in detail, but that I would anonymise some of the contextual information that related to each family. Identifiable information was avoided in the write-up of my findings, not only in relation to names and places, but also in relation to descriptions of behaviour or details such as number of siblings or parents specific professional background. Similarly, in the third study both social care settings were very unique in their set-up and I was concerned about how much information I could include to describe both settings. I feared that too much detail about both settings in terms of their history and working culture risked making them too identifiable and I made the decision to describe both settings only in general terms and to exclude detailed information. However, during the later stages of my analysis, once I had completed all data collection, I began to realise that some of the contextual information that I had decided to anonymise was important to understand my findings. For example, I had decided to anonymise each local authority and names and details of adult service providers. As I moved towards developing overarching themes, questions around 'what is a good adult service?', as well as the role of resources available to people in different areas in Scotland moved into focus. Additionally, I became more aware that differences between the cases were also connected to different resources available to each family based on their different economic circumstances. I experienced a tension between the importance of providing detailed, contextual information, and upholding participants' anonymity. While I was still able to explore and present the transition processes in detail, I realised that I had underestimated the importance of some of the wider background information. At this stage I was not able to go back to participants and I needed to keep my promise of confidentiality, which I had made to participants and which was the basis of their consent to take part in the research. Yet, I need to acknowledge that the exclusion of some contextual details might lead to an incomplete picture for readers.

5.7.3 Involvement of the person with disabilities and consent

Due to difficulties in gaining informed consent people with severe ID are often excluded from being direct participants in research (Hamilton et al., 2017, Palmer and Forrester-Jones, 2016). Arguably, this leads to an incomplete picture, as the people affected are simultaneously the ones that are passed over (Nind, 2013). However, the

attempt to represent experiences of people unable to speak for themselves and give permission to take part in research raises issues of power. The final research output is a construct created by the researcher and therefore the right of researchers to represent vulnerable people can be called into question. I believe that the risk of further marginalizing people with severe ID by excluding them from research and keeping their lives out of public perception outweighs ethical concerns about their involvement in research, yet it is important for researchers to address power imbalances and make their interpretative processes transparent (Mietola et al., 2017, Stenhouse, 2014).

Parents gave proxy consent for their children to be involved in the study, as well as consenting to their own involvement through the consent forms. However, I felt that only thinking about consent in relation to a signature on my forms was not enough. Drawing on ethics of care helped me to understand consent as a relational process and throughout my observations I worked closely with people who knew the person well to help me understand their response to my presence in their life (Mietola et al., 2017, Brannelly and Boulton, 2017, Kittay, 2001). All observations were conducted within education and/or adult service settings, with people close by who knew the person well. Additionally, I closely monitored the behaviour of the person during my observations to remove myself if there was any indication that my presence caused discomfort and was unwanted. Staff at the schools and adult services were made aware that if my presence appeared to be causing any distress, they should let me know and I would remove myself from the situation immediately. This also included any distress caused to other students and service-users. Through this I acknowledged that the person was able to communicate if they felt uncomfortable in my presence and I was able to view them as active agents with the ability to consent within the immediate moment and in proximity to people they knew well. Similarly, Participant Information Sheets made all participants aware that they had the right to withdraw from the study at any time.

5.7.4 Involvement of mothers

So far this ethics section discussed ethical concerns that I was able to consider before the start of the data collection process. However, during my involvement with participants I encountered another dilemma, a dilemma that repeatedly came up for me and which I continue to struggle with. While I had carefully considered how to

involve the person with disabilities, I did not think about the involvement of parents as an ethical issue. Yet, during my involvement with mothers I became aware how much of their time was spent meeting with professionals, looking after their children and advocating on their behalf and how much stress and anxiety they experienced (Dunn et al., 2019). The interdependence between the lives of mothers and their children made a very strong impression on me. As has been found by others, the perspectives of mothers became central to my understanding of transitions and the lives of people with severe ID in adulthood (Rogers, 2016, Porter, 2006, Kittay, 2001, Hubert, 1991). Mothers cared deeply for their children and their accounts included moments of joy and love, but there were also accounts that portrayed the hardship of caring for their children. This led to me feeling guilty for taking up more of their time during the research process. Although all mothers were welcoming and did not voice concerns themselves, I often struggled with the question: 'How does this research help them?' On a number of occasions some mothers asked me what I attended to do with my research. I usually answered that I would try and speak about it at conferences and that I was hoping to publish articles, but when hearing my own answers, I was wondering if that would be enough and if my research was rather benefitting me than them. I feel that my own sense of helplessness when faced with the stories of each family, closely mirrored a sense of helplessness that was felt by many participants, reflecting a narrative of: 'This is the system. There is just not enough money. What can we do?' In the end the responsibility I felt towards mothers and their generosity to share their experiences with me motivated me to reach out to policy and third sector providers to share my research findings with them and I was able to secure funding from the Action Trust of the University of Edinburgh to record an audio play to try to communicate about my research more widely and in a more accessible ways (see appendices). Yet, I still wonder if it is and will be enough.

5.7.5 Insider research, reflexivity and transparency

Insider research is relatively common within the caring professions, including studies involving people with intellectual disabilities or dementia (DeZonia, 2008, Wagemans et al., 2013). Insider research has been linked to benefits such as having a greater understanding of the phenomena being studied and being less intrusive with researchers knowing how to best approach people, as the researcher is familiar with the context (Hodkinson, 2005, Unluer, 2012). Although I had stopped working within

the field of intellectual disability for more than a year before my research started, it can still be classed as insider research. I worked within the field of severe ID for nine years previously to undertaking my PhD research and I had some previous relationship to a number of educational and care service settings that were part of this research. I did not have any previous relationships with any parents or young people and adults that were part of this research, except for Tom. I had worked with Tom on three occasions while covering shifts at his respite service through an agency a year before I started my research. I never had contact with his parents nor his school at the time (the recruitment organisation) and I did not anticipate his involvement in the study. Discussions with my supervisors and drawing on ethics of care helped me to see my previous relationships to people and organisations as an advantage instead of a limitation. For example, having met Tom before allowed me to consider how conducting the observations would work best for him. Overall, I experienced my previous professional knowledge and experiences as positive. I believe that it helped to reduce the likelihood to cause distress and to be intrusive. I was familiar with procedures and felt at ease in the different settings I visited, which helped me to build relationships with participants.

Although my findings are inherently linked to my own past, experiences and beliefs, I employed a number of techniques to help me reflect on my interpretations and inferences throughout. I worked with preconceived ideas and assumptions during data collection and analysis by using reflective practices and by including reflections from fieldnotes within the write-up of my findings. Drawing on life story research, narrative profiles and ethnography during the analysis phase helped me to develop an approach that was able to highlight my role in re-telling and presenting an account of each transition and the people who were part of it (Atkinson, 2015, Eriksson et al., 2012, Grove, 2012, Henderson and Bigby, 2019, Ledger, 2012, Stenhouse, 2014, Seidman, 2006). For example, I decided to present my observation data from my own perspective, writing myself into the findings and including reflections on what it was like to conduct the observations. In combination with extracts from my fieldnotes this helped to make my own role transparent and to acknowledge at all times that I was talking about the lives of people as seen and experienced by me and those close to the person with severe ID. I believe that this leads to a transparent and authentic

account by making the situational conditions of the research process visible (that is, by explaining what it was like to be the researcher).

5.8 Case study analysis: Study one and two

The analysis of multiple case studies starts with an in-depth exploration of each case and context (within-case analysis), before slowly moving to a synthesis of the data across cases (cross-case analysis) (Yin, 2003). The beginning of the analysis involves following processes in detail and working closely with context. Maxwell (2012) identifies such analytic approaches as ‘contiguity-based’ and contrasts them with thematic approaches to data analysis. In thematic approaches interview and text sequences are coded and recoded into smaller units and therefore their meaning can be decontextualised because categories instead of process frame the analysis and categories start to replace the original connected data structure (Maxwell, 2012). In case study research, thematic approaches and contiguity-based approaches are not incompatible but seen as complementary to one another. They are helpful at different stages during the research process (Yin, 2003). An in-depth understanding of each case’s story is an important step at the beginning of the analytic process, while the development of themes comes at the end, once the specific context of each case has been established (Miles and Huberman, 1994). This helps to ensure that both researchers and readers do not lose *‘the local web of causality’* (Miles and Huberman, 1994, p. 151) and that themes retain clear connections to the context of each individual case.

In the following section I will discuss how my analysis started with an in-depth exploration of the transition journey of each person, this was followed by a closer examination of people’s support networks during transitions through the use of proximity displays. Lastly, I will describe how I synthesised findings across cases utilising Bronfenbrenner’s ecological framework.

5.8.1 Within case analysis: Six transition journeys

(...) all empirical research studies, including case studies, have a story to tell. The story differs from a fictional account because it embraces your data, but it remains a story because it must have a beginning, end, and middle. The

needed analytic strategy is your guide to crafting this story, and only rarely will your data to the crafting for you. (Yin, 2003, p.130)

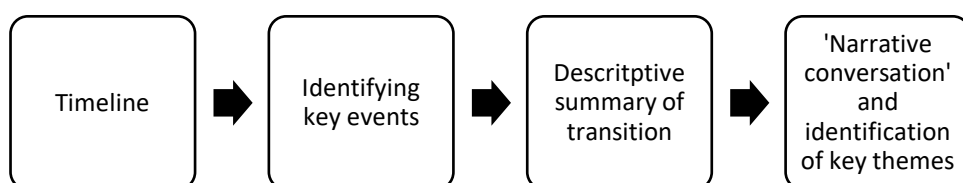
Emphasising the narrative component of qualitative case study research, a linear approach to understand each transition process, following beginning, middle and end, was deemed the most helpful for this study. My aim was to offer a detailed description of each transition, by firstly illustrating process and context (the 'how'); and, secondly, by exploring underlying reasons and influences (the 'why').

Using a narrative approach might appear to involve little analytic know-how, being merely a representation of the data, but the development of a coherent narrative from vast amounts of qualitative data – data that can often seem fragmented and disjointed – requires skill (Yin, 2003). Maxwell (2012) argues that the development of case narratives does not merely describe the data but also helps to:

analyse and reduce data; this is generally done by identifying key relationships that tie the data together into narrative or sequence, and eliminating information that is not germane to these relationships. (p.115)

Thus, key relationships within the data played a crucial role in describing the complexity of each transition process and in highlighting key-decision and key-events. I began my analysis by developing timelines of each transition process. The timelines were the foundation of my analytic strategy and helped me to identify what happened during the transition and who was involved (see figure 11). The next steps in the analysis were the identification of key events within the timelines and creating a descriptive summary of the transition process. This was followed by what I called 'narrative conversations', which explored the transition process in more detail from the perspective of different people involved and reflected on key themes that were apparent in interviews. In the following I will introduce the coding strategy that informed each analytic step before discussing the development of timelines and my 'narrative conversations' in more detail.

Figure 11: Analytic process within-case analysis



5.8.1.1 Coding strategy

My coding strategy involved coding all interviews, documents, observations and fieldnotes for: (1) Characters; (2) Time, (3) Events, (4) Key-events/Turning points and (5) Key themes.

The following table illustrates the coding process (table 22).

Table 22: Coding strategy

CODES	RESEARCH QUESTION *helps to illustrate	EXAMPLES
Characters	WHO – Important characters; Relationships between characters	Names, pronouns, the first person (“I”), experiences or events involving other people
Time	WHEN – Historic context; Sequence of story; Experience of time	Dates, Years, Conjunctions of time (after, before, when...), Time periods (weeks, months, days), Historic events
Events	WHEN and WHAT – Sequence; Interactions, Process, Decisions made	Meetings, Phone calls, Actions, Conversations with others
Key-events	HOW/WHY – Connections and Relations; Interactions; Turning points; Wider influences	Strong emotions surrounding event, Link to important decision that is made, Change in narrative after event
Key-themes	HOW/WHY – Wider influences; Experiences; Concerns; Phenomena of interest	Deductive: Pre-defined themes of interest (Involvement of person with severe ID) Inductive: Themes emphasised by participants. Instances where interviews move away from the structured questions and where participants take the lead to share their thoughts and experiences.

5.8.1.2 Timelines

Timelines were developed based on my coding strategy (see table 22). Events that were mentioned in interviews or which were described in case specific documents were included in the timelines. After the first two or three interviews, I started by drawing a timeline of the transition. Events and occurrences that were mentioned in first interviews or documents were subsequently checked with other participants to confirm if an event or process had taken place. There was no occasion where participants disagreed, but at times participants needed to refer back to their files to confirm exact time frames or dates. Towards the end of the data collection process in each case I took the timeline that I had drawn with me and discussed it with mothers during the last interview and at least one professional to validate each timeline.

Using the timelines in interviews changed the dynamic of them. Participants engaged differently with questions about the sequence of events compared to previous interviews. Having a visual representation of the whole transition process seemed to help participants to clarify sequences of events, particularly those that had happened several years ago. Additionally, the timelines elicited reflections on the transition process as a whole. On several occasions participants identified certain events or occurrences in the timeline as turning points or pointed out their particular significance without being prompted to do so. For example, when being shown the timeline Emma's social worker pointed to the respite transition and declared that this was the process that had 'really let Emma down'.

Some events had specific dates that were used in the timeline, while others were processes that had no fixed single start and end date but were described as occurring in a specific week, month or year. Thus, the timelines are not exact representations but give a very close depiction of the process. Timelines were first created by hand, then during the analytic process I digitalised them using Microsoft Excel (2011) and printed them in an A1 format. Having large prints of each timeline allowed me to highlight key events and people involved in events such as meetings or decisions made while transcribing my interviews. To accompany my timelines, I created short descriptive summaries of each process and I later used Adobe Illustrator (2012) to translate the timelines into an A4 format. Those will be used in the findings chapter. An example of a bigger Excel timeline can be found in the appendices

5.8.1.3 Narrative conversations: Transition collage

During the first analytic steps, while emerging myself in the interview data, I noticed that certain elements of the interviews were ‘talking’ to each other. In interviews, for example, people were referring to the same events and decisions. Thus, I decided to use my timelines in combination with my interviews, fieldnotes and observations to explore the development of ‘narrative conversations’. By arranging extracts from interviews, observations and fieldnotes in accordance to the timeline of each process, I created narratives that depicted each transition process from the perspectives of different people involved, including my own. I used key events and key themes that I had identified in each case as headings to introduce different aspects of the decision-making process. To illustrate the perspectives of different people I inserted extracts from interviews, using participants’ own words, as well as extracts from my observations and fieldnotes. Thus, the narrative conversations include data that stays largely verbatim. The development of ‘narrative conversations’ was influenced by life story research and Seidman’s (2006) ‘narrative profiles’. Both involve a representation of the data that stays close to participant’s own words. The use of narrative conversations allowed me to also include my own perspective as the researcher or narrator by including extracts from the vignettes I had written during my observations and reflective extracts from my fieldnotes. One of my main aims was to involve people with severe ID within the research. I was unable to include their views directly and instead relied on my own account of meeting each person and talking to those close to them to depict a picture about their lives. While the person with severe ID is at the centre of the transition process, my portrait of their journey is an indirect one through my own narrative and the narratives of those involved in making decisions for them; parents, social workers, teachers, adult service staff, health professionals, and local authority managers. Mietola et al. (2017) argue that in the context of severe ID it is of the greatest importance that researchers’ attempt to create methodologies that make the research process transparent and take into consideration ethics of representation. I believe that by bringing my own voice into the write-up, the research process becomes visible within the portrayal of the transition process. Thus, the narrative conversations reflect the experience of the research process and make both participants’ and my own perceptions transparent.

5.8.2 Examining people's relationships and involvement in the transition through proximity displays

To explore relationships and people's involvement in the transition process I asked mothers, and in one case, one of the professionals, to create proximity displays using cards that represented the people who were involved in the transition process. In the first study I asked mothers to place cards to visualise (1) how close people were to the young person with severe ID and (2) how involved they were in the transition /decision-making process. I prepared cards of main stakeholders beforehand but also included blank cards for additional people to be added. In the second study I developed the task further to account for different aspects of the transition process. This time I asked mothers to create three displays to illustrate (1) how closely people were involved in the life of the person with severe ID, (2) how closely people were involved in organisational decision-making processes (funding, placements decisions) and (3) how closely people were involved in supporting the practical move into supported accommodation.

Figure 12: Example proximity display from study one. Question: How closely involved are people in the young person's life?

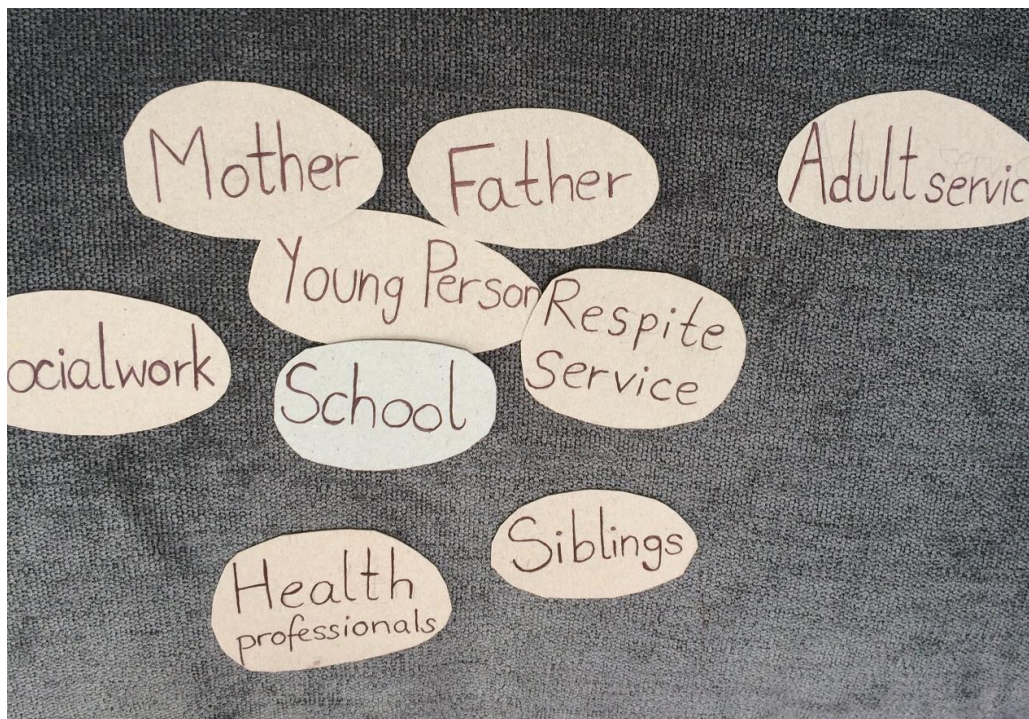
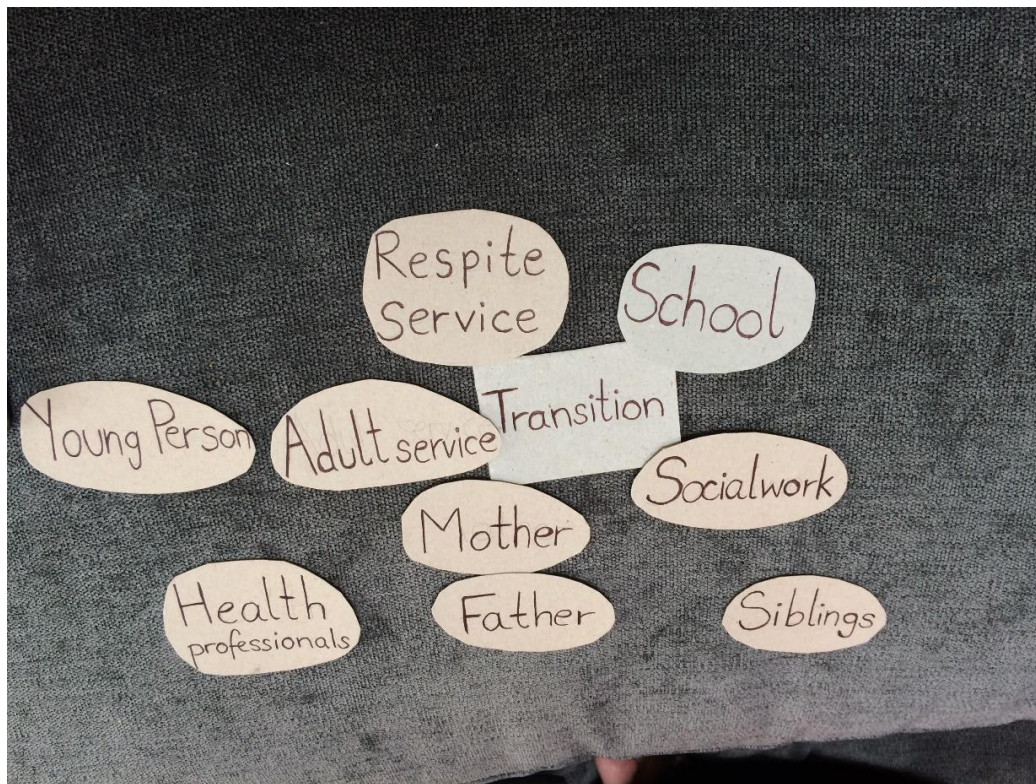


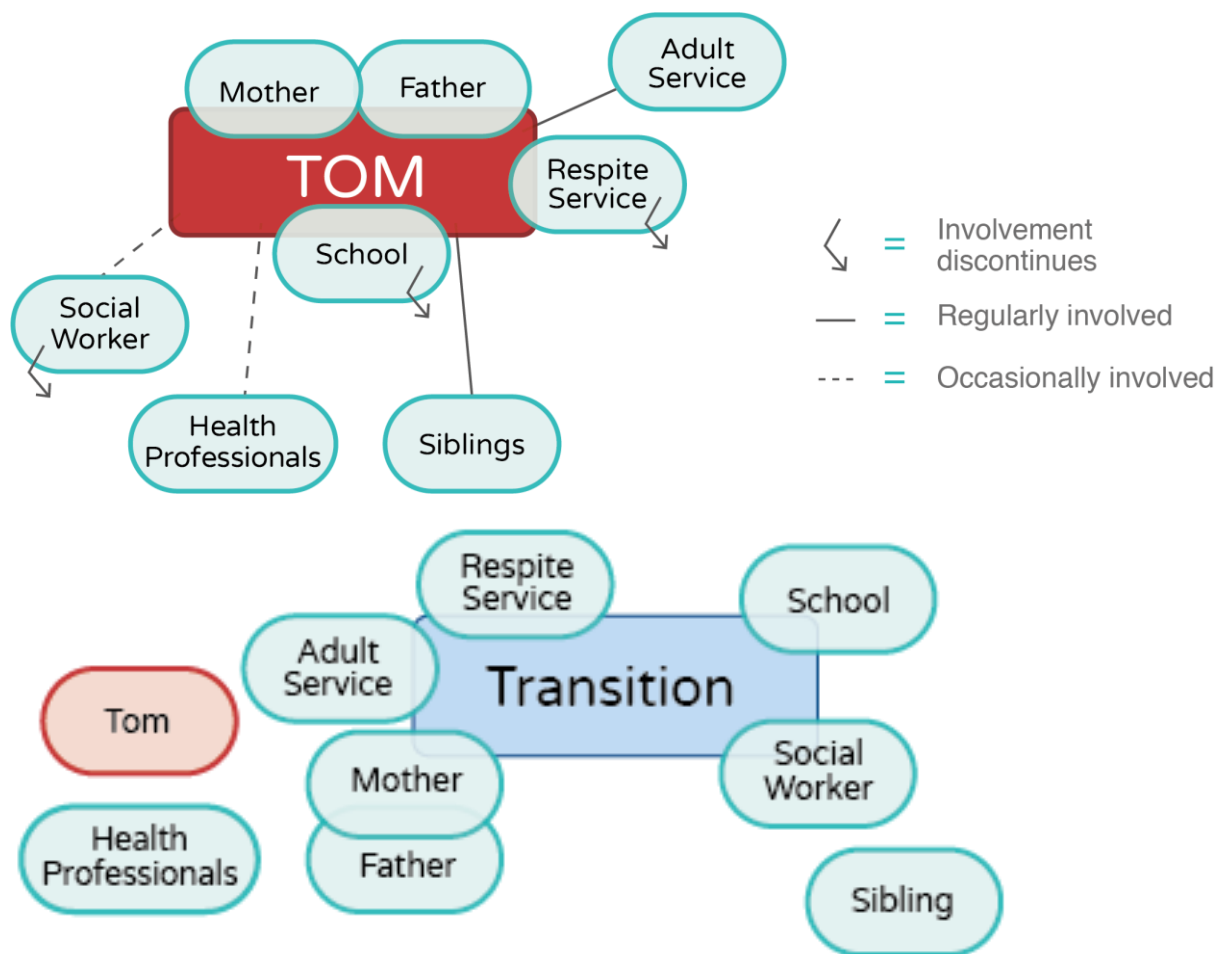
Figure 13: Example proximity display from study one. Question: How closely involved are people in the transition process?



Conceptualising the involvement of people in decision-making processes, who are mostly non-verbal, is difficult. In interviews participants can be at risk of giving clichéd answers that reflect the standard discourse (Bagnoli, 2009). People with severe ID are often described as passive and dependent, unable to participate in decision-making processes. During some of my interviews I noticed that participants struggled to talk about the involvement of the person, swaying between narratives that seemed to reflect policy discourses of person-centeredness and rights-based approaches or narratives that conceptualised the person as unable to be involved. Using visual displays allowed participants to share their view on the involvement of the person in a different way, providing interesting contrasts between sections in earlier interviews that had explored the involvement of the person.

I took pictures of each display and later on during the phase of analysis I digitalised and anonymised them using Adobe Illustrator (2012), adding further information about the consistency of people's involvement based on my interview data.

Figure 14: Digitalised proximity displays study one



5.8.3 Cross-case synthesis utilising Bronfenbrenner's framework

Framework analysis was used in the systematic review and all three studies to facilitate an ecological understanding of the data. Framework analysis combines deductive (a-priori framework) and inductive (subsequent line by line coding) approaches to analysis (Carroll et al., 2013, Snilstveit et al., 2012). During the analytic process Bronfenbrenner's ecological model was modified in response to new evidence that was explored in each study, so that the final product in each study was a revised framework that included both modified themes and new themes (Stuart et al., 2017, Richie and Spencer, 1994). Involving line-by-line coding, framework analysis helped to bring existing categories alive with data from the concrete context of each study. Additionally, I was able to make the analytic process transparent and accessible to others, by visualising amendments made to themes and subthemes (see tables 23, 24, 25) (Richie and Spencer, 1994).

5.8.3.1 Analytic process

Framework analysis involves four analytic steps: (1) Familiarization with the data, (2) Coding and applying the framework, (3) Charting and developing the framework and (4) Interpreting the data (Gale et al., 2013, Satherley et al., 2017).

Familiarisation with the data: I had worked closely with my data during the within-case analysis. Additionally, as I had transcribed all interviews myself, I was very familiar with my data.

Applying the framework: Each ecological level was translated into codes using Nvivo11. In the systematic review only the six ecological levels were translated into codes (The Individual, Microsystem, Mesosystem, Exosystem, Macrosystem, Chronosystem) and subthemes were created during the analysis. In study one and two subthemes that had been identified in the previous framework were translated into codes as well. In study one and two the coding stage involved going back to all interview transcripts, documents, fieldnotes and observations line by line. Extracts that did not fit existing subthemes were given new codes. Thus, during the coding process the ecological levels remained the same while the new subthemes were created within each level. Interview transcripts informed the coding of all ecological levels, while other data sources complemented the interview data and helped to explore themes and influences in relation to specific levels. For example, general documents complemented the development of subthemes within the Exo- and Macrosystem, while the observations complemented the development of themes in relation to the six adults and their Microsystems.

Developing the framework: During the coding process subthemes were expanded and additional codes were created in relation to each ecological level. Particular attention was paid to new codes and content that did not fit existing subthemes to explore the need to make changes to the framework, by adding new subthemes or renaming existing ones. For example, reflecting the focus of study two, the subtheme 'Becoming an adult' in study one was renamed 'Being an adult'. Thus, codes were arranged, rearranged or renamed, and the summaries were developed further. This involved close discussions with my supervisors based on the developing summaries and coded data.

Interpreting the data: The last stage involved building up a picture of the findings as a whole and exploring connections between ecological levels during the interpretation

of the data (Ritchie and Spencer, 1994). During this last stage I made use of my reflective fieldnotes and separate notes I had taken throughout the analytic process to note down ideas and early interpretations of the data (Gale et al., 2013). It was important to discuss different stages of my writing with my supervisors to get feedback on my interpretations and ensure that my inferences were grounded in the data. Regular discussions provided peer-review and helped me balance a more general and theoretical analysis and reduction of data with the need to stay true to the accounts of participants (Gale et al., 2013). I had kept earlier stages of my writing and pages long of coded interview extracts for each ecological level and I went back to them once I had finished a final draft of my interpretation to check if my inferences still illustrated what participants had shared with me.

5.8.3.2 Changes made to Bronfenbrenner's framework

In the systematic review, Bronfenbrenner's (1979) model was applied across studies. Based on the data from the systematic review, subthemes were developed for each ecological level. The application of Bronfenbrenner's model in the systematic review led to the development of fourteen subthemes across Bronfenbrenner's ecological levels (see table 23).

Table 23: Systematic review a-posteriori framework (a-priori framework in study one)

Ecological levels	Subthemes
The Family	The young adult Parents Quality of life
Microsystems (Changing Networks)	Ending school Perceptions of adult services Additional networks
Mesosystem (Decision-making and Collaborative Practice)	Choice and information Roles and relationships Involvement of the young person
Exosystem (Organisational context)	Coordination of services Budget and funding processes
Macrosystem (Society)	Culture Politics and economy
Chronosystem (A life-course Perspective)	From past to future

In study one, the ecological levels and the fourteen subthemes that had been developed in the systematic review were applied to my data and during the coding process the subthemes were revised and renamed (see table 24; new themes highlighted in red). In the second study the subthemes identified in study one were applied to the data, again leading to a revised version of the framework, reflecting the specific context of each study (see table 25; changes highlighted in red).

Table 24: A-posteriori framework study one (and a-priori framework in study two)

Master Theme	Subthemes
The young person	Likes and needs Becoming an adult: changes
Microsystems	Family Professional environment Additional networks
Mesosystem	Practical transition Collaborative practice: Concord and conflict Involvement of young person
Exosystem	Organisational transition Information and Choice Involvement of young person: Parents as advocates
Macrosystem	Culture Politics and economy
Chronosystem	A life-course perspective

Table 25: A-posteriori framework study two

Master Theme	Subthemes
Adulthood: Ben, Lisa and Luke	Life within adult services Being an adult
Microsystems	Family Professionals

	Additional networks
Mesosystem	Practical transition Involvement of person Collaborative practice
Exosystem	Organisational processes Involvement of person - Advocacy
Macrosystem	Politics and economy – The policy gap Culture
Chronosystem	Future responsibility – Who will care?

As the focus on transitions from school to adult services changed from the systematic review and study one, towards exploring transitions within adult services in study two, subthemes were changed to reflect the different contexts. For example, the subtheme 'Life within adult services' was added to the framework in study two and the role of adult services in supporting the person was highlighted in relation to the subtheme 'Advocacy' within the Exosystem. Overall, during the coding process the ecological levels remained the same and data was mainly coded in relation to subthemes. However, the first ecological level was renamed in study one and two compared to the systematic review. In the systematic review the decision had been made to have the family as the first level, because there was little data that related only to young people, reflecting an emphasis on the perspectives and experiences of parents in the included studies. My own data in study one and two allowed me to have the person within the first level and to include data that related to the family within people's microsystems.

5.9 Analysis study three

The analysis of study three built on my work in study one and two. I started by describing the two settings and crafting narrative profiles of transitions in old age of three men to provide context to the work of participants and give examples of transitions that had been shared with me (Seidman, 2006). Later on, framework analysis was used to explore the experiences and practices of social care professionals across ecological levels, utilising Seedhouse's (2009) ethical grid with its focus on ethical decision-making.

5.9.1 Profiles of three transition journeys

To provide context to the third study a descriptive summary of both social care settings was written based on my interviews, my visit to both settings and publicly available information. Additionally, I crafted profiles of the transition journeys of three men with intellectual disability to provide examples of the kind of transitions participants were supporting in their setting. During interviews a number of participants discussed their experiences of supporting three men who had passed away in recent years in more detail. I decided to craft summaries of the three journeys based on Seidman's (2006) narrative profiles and life story research (Ledger, 2012, Plummer, 1995). Sections in interviews that referred to the three transitions were highlighted and then arranged in chronological order. Participants own words were used as much as possible to craft the three profiles, while I needed to slightly change participants wording to summarise larger sections from interviews. Participants who had accompanied the three men received the three profiles and reflected that they were representative of their experiences of supporting them.

5.9.2 Synthesis of data – utilising Seedhouse's ethical grid

In the third study I decided to use Seedhouses' ethical grid (2009) instead of Bronfenbrenner's (1979) framework to synthesise my interview data. Bronfenbrenner's ecological model provides a clear conceptual framework, but it is general and not context specific. It consists of broad layers and does not include subthemes or processes. While this was an advantage in the first two studies and allowed an exploration of the specific context of each study, it was felt that the focus of the third study was tighter and would benefit from a more detailed framework.

Seedhouse (2009) developed the ethical grid as a tool to help healthcare professionals to reflect on ethical decision-making. The advantages of the grid are that it offers an ecological perspective to decision-making and therefore has a clear link to Bronfenbrenner's framework, which was used in the other two studies. Yet, Seedhouse's grid is more detailed and has an emphasis on the decision-making of healthcare professionals, more closely reflecting the focus of the third study.

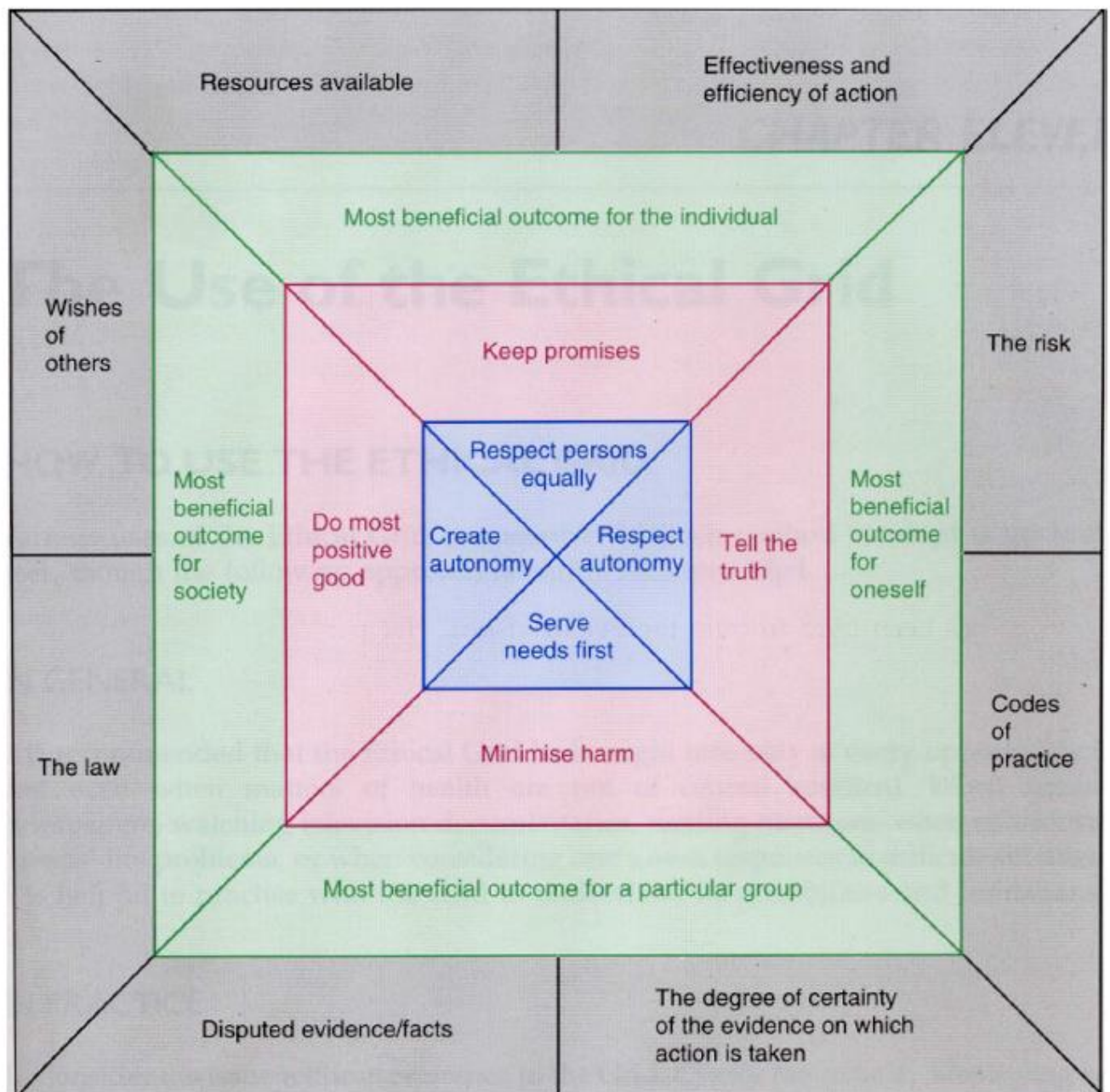
While Seedhouse's ethical grid is primarily used in practice and teaching (Lovett and Seedhouse, 1990, Seedhouse, 2009) it has been applied, amongst others, to analyse data or evaluate practice in the context of end of life decision-making (Kuhl and Wilensky, 1999), interprofessional teamworking (Wiles et al., 2016), ethical considerations to research methodologies (Stutchbury and Fox, 2009), social work practice (McAuliffe and Chenoweth, 2008) and prescribing practice (Amoroso and Otway, 2006). By applying it to my data it was hoped that the grid could be developed to give greater clarity to how decisions are made by social care professionals in the field of intellectual disability and old age. The grid consists of four layers (table 26) to illustrate different levels that should or will influence ethical decision-making.

Table 26: Layers of Seedhouse's ethical grid

Core	The individual and his or her needs and rights are at the centre
Deontological	Is concerned with the way in which things are done and the duties and obligations professionals experience.
Consequential	Encourages to think about the consequences of possible actions for others.
External	Includes external influences across Macro, Exo and Mesosystems including laws, codes of practice, available resources as well as collaborative practice with families and other professionals.

Each layer contains subcategories in boxes (figure 15). Although the boxes are separated, Seedhouse (2009) stresses that in practice, layers and boxes will be interdependent and overlap.

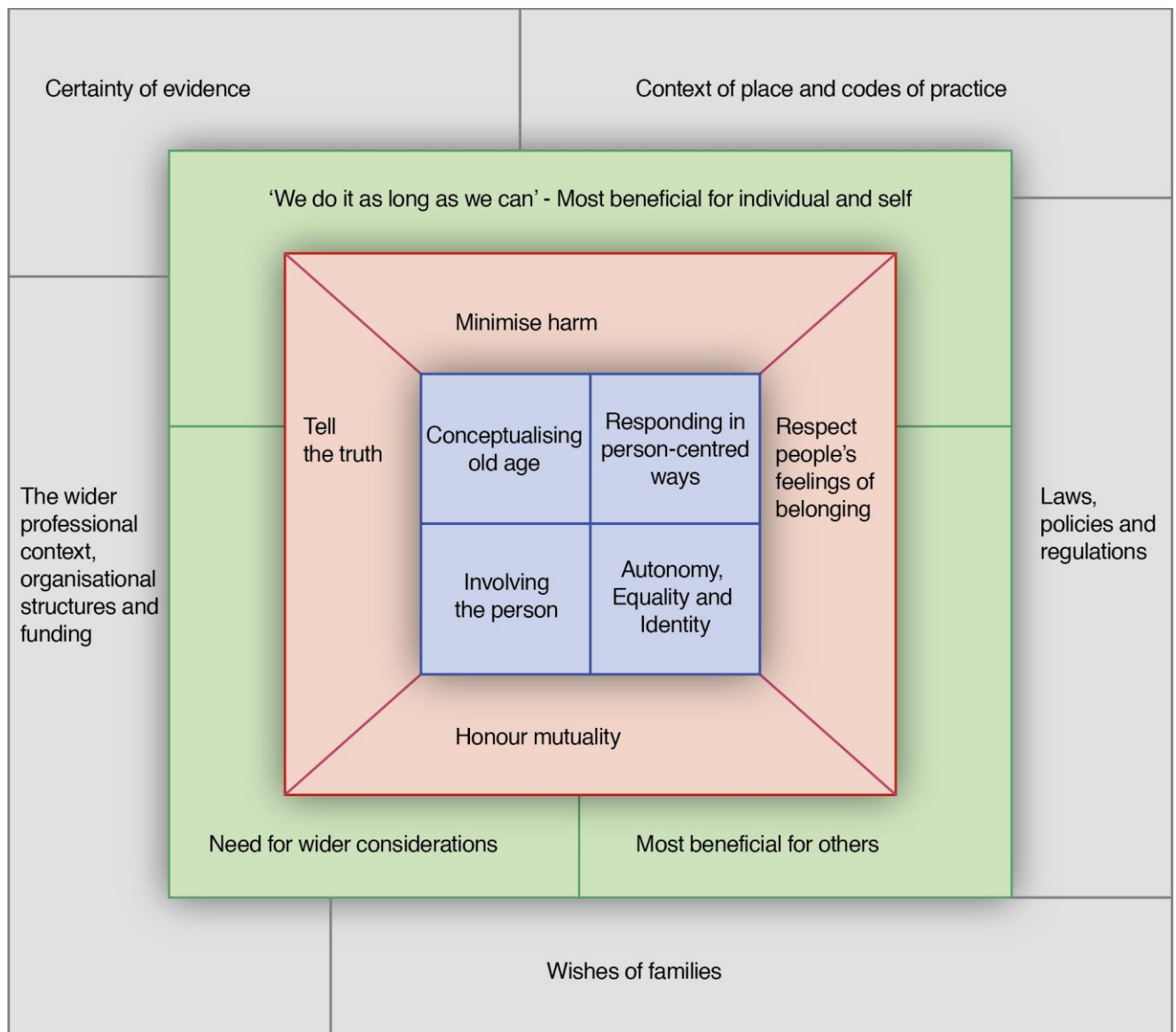
Figure 15: Seedhouse's ethical grid – sub-categories (Seedhouse, 2009, p. 164)



The grid fitted the data well and helped to explore different decision-making processes. I was able to capture nuances across ecological levels, including participants own values and emotions; needs, preferences and likes of the people they supported; relationships between participants and the people they supported; as well as wider influences such as available resources and organisational processes. A number of changes were made to the grid (see figure 16). As a result of the combination of deductive and inductive coding that is

central to framework analysis many of Seedhouse's boxes were renamed or further developed to move away from their general quality to reflect the specific context of this study (Ritchie and Spencer, 1994).

Figure 16: Revised grid - A-posteriori framework



6. FINDINGS

My data was complex, involving different data sources and exploring transitions from different viewpoints across three studies. I put a lot of thought into how to best present my findings, to allow the reader to grasp the complexity of the included transition journeys, while not getting lost in them. Study one focused on young people leaving school and entering adult services and study two was concerned with people's transitions within adult services. Both studies followed identical analytical steps, exploring different levels and aspects of transition processes. Therefore, findings from study one and two are presented conjointly, taking account of their close connection to each other, while still visibly separating findings. Findings for each of the two studies are examined in three sections. The chapter begins with an in-depth discussion of the six transition journeys (within-case analysis). Next, I present the proximity displays that were created with mothers and one social care professional, to closely examine people's support networks and involvement in the transition process, focusing on the involvement of the person with severe ID. This is followed by an ecological exploration of the transitions in both studies (cross-case analysis) utilising Bronfenbrenner's ecological model. After each section main themes are summarised, compared and put into context. Thus, the chapter will follow a movement that travels from the inside out, starting with a detailed examination of each individual case and then moving towards a thematic understanding of findings across cases.

Study three was conducted in a different way and is presented at the end of this chapter. The transition journeys of three men are presented as examples of transitions in old age, followed by an exploration of how social care professionals experienced and described transitions in old age. Utilising framework analysis, Seedhouse's ethical grid is used to explore transitions in old age across ecological levels. The use of an ecological perspective throughout builds a connection between the findings of each study. All three studies focus on how decisions are made by people at times of transitions, how the process is influenced by wider systems and how the person with severe ID is involved. 'Small' discussion sections will be included in this chapter, where specific findings to each study will be discussed in light of existing literature and research. The

main discussion chapter will go deeper to explore main themes and findings across the three studies through different theoretical lenses.

6.1 Study one and Study two: Transition journeys – Six cases

The first part of the findings chapter presents case studies of six adults with severe ID and their transition journeys. Timelines are used to describe what happened in each case and to highlight key-events that influenced outcomes. Drawing on interviews with multiple stakeholders and my observations, the transition process is examined from multiple perspectives, including my own. By using extended sequences from interviews, observations and my fieldnotes it is hoped that the reader will get an insider perspective and a sense of the complexity of each transition journey.

6.1.1 Study one: Three transition journeys from school to adult services

The first study presents the transition journeys from school to adult services of Tom, Emma and Peter. Both Tom and Emma were in the midst of the process of leaving school, while Peter had moved to his new adult service one year previously.

6.1.1.1 Tom

In the following I will present Tom's transition journey. When I started the process of data collection in the spring of 2017 Tom's transition had just made a sudden turn. He had been due to leave school in the summer of 2018 when a decision was taken for him to leave one year earlier to allow him to get a space at a specialist local authority run adult day service. His case was in some sense the most complex one in relation to the specific support that Tom required. His family received support from a number of health and social care services, which had allowed Tom to live with his family throughout his teenage years. His parents wanted Tom to continue to live with them but were worried about a decrease in support, which they were facing within adult services.

6.1.1.1.1 Case description and timeline

At the start of the study in 2017 Tom lived at home with his parents and siblings. He went to a special needs school within his local authority and attended a local respite service. Everyone I met and all the documents I read described Tom as a very complex case, as he had multifaceted sensory and mental health needs. Tom required close supervision, mainly due to the high levels of self-injurious behaviour he engaged in almost on a daily basis. I had met Tom before and spent roughly three days in his company when I worked for a couple of months at his children respite service in 2016.

FIELDNOTE: *I remember Tom very vividly. He is one of the young people I met during my short time at the respite service who made a strong impression on me. I always feel an initial strangeness when I am asked to support someone who I have never met before in very intimate ways, especially if the person does have little verbal communication. I remember that he came from school and we sat down at the table where he had his dinner. He did not talk except for repeating a few words I said. 'Toast', 'Juice', 'Please', which he pronounced quick and quietly. When we were inside the building of the respite service, he always carried his visual timetable in both hands while moving around. Staff often gave him something to carry in his hands to prevent him from self-harming. I remember that staff seemed very caring and committed towards him and he responded well to those he knew well, smiling, repeating their words and having good eye contact. (...)*

The severity of his self-harm was stressed to me when I was briefed about him and I remember how it left me nervous when meeting him for the first time I only ever witnessed a few self-harm attempts and he was distracted fast, but I could feel the fear of it being able to escalate within myself and other staff. His head was thickly bandaged when he came from school on one of the days I worked there. I remember watching movies with him, baking, going shopping and going for drives towards the seaside. I wonder if he recognized me when I visited him in school. I don't know and I think I have no way of knowing. (case 1, Tom, May 2017)

The following table will give an overview of Tom's transition journey.

Figure 17: Transition journey Tom

2014	• Family starts to look for information about transition	Tom: enjoys art, walks, sensory activities, taking the bus to the local library and spending time with his family. Music and watching favourite cartoons and video clips seems important to him. He can say a few words but mainly communicates through his behaviour, noises, facial expression and with support is able to use picture exchange to communicate his basic needs. When I get involved Tom has two more years at school, but as he is about to turn seventeen he is approaching a transition from respite services for children, to respite services for adults. In his local authority respite transitions happen at the age of 17 and therefore the respite transition usually happens up to a year before the transition from school. This will result in a significant reduction in respite days. Tom's parents want Tom to continue to live with them but feel that they need sufficient support and respite to be able to do so. There is only one adult respite service in the local authority that is able to support Tom and that offers overnight stays. As a place becomes available at the service for summer for both day and respite care, his parents take the decision for him to leave school one year earlier than had been planned. Its fees are lower than the previously favoured day service and so the budget allows for more respite provision. Additionally, this will mean that Tom accesses one service instead of two, providing greater consistency. The service seems able to meet Tom's needs but in an ideal scenario, he would have more time there. The cut in respite is a big concern for his family, who worry how it will affect both Tom and the whole family.
Early 2016	• Mother visits three local adult services. Finds one service suitable (service B)	
Nov 2016	• Transition social worker (SW) allocated	
Dec 2016	• Review meeting at school • Social work assessment starts	
March 2017	• Review meeting at school • Conversation with service B about Tom. Service at full capacity with waiting list in place • Confirmation of respite transition by the end of summer • Senior SW management offers place at service A • SW offers placement to parents	
April 2017	• Parents accept placement at service A • School is informed about Tom leaving this summer • School staff prepare transition and contact service A	
May 2017	• Service A staff start to shadow Tom at school • Service A speaks to parents and children respite about Tom • Speech and language joint support for service A staff	
June 2017	• Tom begins to visit service A supported by school staff	
July 2017	• Tom leaves school and starts at adult service A	
Oct 2017	• Clinical psychologist and psychiatrist offer support to service A • Meetings to prepare transition from children respite to service A • Respite transition and reduction of nights by more than half • Transition to adult social work	

As can be seen in the timeline, from the second review meeting in the beginning of March 2017 till Tom left school in the beginning of July the same year, most decisions were made. Conversely, the gap between Tom's mother starting to plan and think about the transition in 2014 and the allocation of the transition social worker in November 2016, resulting in the formal start of the process, spanned two years where there was little activity in relation to Tom's transition. Additionally, his transition did not comprise one move but four subsequent changes: (1) the transition from school to Adult Service A in July 2017, (2) the subsequent respite transition a few months later, (3) the transition to adult social work services and the stop of involvement from the Transition Social Worker after a final review and (4) an anticipated health care transition once Tom turned 18.

6.1.1.1.2 Narrative conversation: Transition collage

I interviewed eight people who were involved in the decision-making process to different degrees and who supported Tom in the transition. Everyone except the local authority manager had direct contact to Tom and his family. Their roles in the transition and in Tom's life are summarized in the table below. After the table I will present the narrative conversation, taking a close look at the transition process by connecting data from multiple sources and perspectives. Sub-headings are used to highlight key-events and key-themes within the transition process.

Table 27: Introducing the actors – Tom's case

Actors	Role description
MOTHER	Tom's mother is his main carer. She works within health and social care. Tom's father also cares for Tom. The couple have several other children, both younger and older than Tom.
HEAD TEACHER AND CLASS TEACHER	His head teacher has known Tom for five years. His class teacher took over the class in the beginning of summer. Tom goes to school five days a week and also attends

	the after school club which runs till 5pm on most days
CHILDREN RESPITE KEY WORKER (RESPITE)	His respite service, Children Respite A, provides a second important environment next to his home and school. His key-worker has worked closely with Tom for the past five years. When he came to the respite service his family was at a point of crisis. The extensive involvement of the respite service has been very important for the family.
TRANSITIONS SOCIAL WORKER (SW)	He was allocated to Tom in November 2016. He has met Tom and communicates closely with Tom's parents. Once the transition is completed and reviewed his involvement will stop.
CLINICAL PSYCHOLOGIST	Tom's Clinical Psychologist works closely with his respite service and has contact with his school, parents and other health professionals involved with Tom. Tom has been known to the mental health service since he was a young boy.
ADULT SERVICE SENIOR STAFF MEMBER (ADULT SERVICE)	She is a senior-member of staff at Adult Service A, a local day service. Once it was decided that Tom would transition to the service this summer, she began to coordinate his transition.
LOCAL AUTHORITY DISABILITY MANAGER (MANAGER)	Within the authority's health and social care partnership, he is responsible for people with learning and physical disabilities. He manages the social work transition team and oversees allocated budgets.

Lack of information early on

Tom's mother started to think about and plan for the transition two years before the start of the formal process in 2016. Lack of practical support at this stage

caused her stress, especially in relation to a lack of information on available services for someone as complex as Tom.

MOTHER: *Initially when we tried to get involved with the transition, we were told that it would come naturally. You have got no idea what is out there so at least if someone said to you look there is this place, don't worry for another four years. (...) We have been to look at quite a few places and I have to say that most of them for Tom were very unsuitable. It was good to go out and look at these things, very friendly and welcoming. All the places were. It is just the fact that the more you go down the line, the more you realise quite how disabled your child is. Profoundly disabled in all areas in that there is not much out there that is going to help. It is a difficult, difficult time, because the reality sinks in a bit more.*

The transition process started formally when a transition social worker was allocated to Tom and his family at the end of 2016.

SW: *We always knew that Tom would be transitioning respite on his seventeenth birthday, but we sort of expected that he would probably leave school next summer if not this Christmas at earliest.*

Respite transition

The respite transition played a crucial role in the decision-making process. Tom received the maximum amount of respite allocation in children services and the maximum amount of respite in adult respite services was less than half of that in children services. Tom's parents were clear that the respite provision allowed the family to have Tom at home and a decrease in nights in adult services was a major concern for them.

MOTHER: *When he does kick off now, he is six foot nearly, so it is a lot harder than when he was ten, so it does become more difficult. That is the irony of it isn't it, you are dealing with someone who is more difficult.*

Concerns about the respite reduction were highlighted in both his review meetings.

HEAD TEACHER: *The big debate was about the respite.*

CLINICAL PSYCHOLOGIST: *I wrote a letter earlier this year to voice concerns about that and the impact that that might have on the back of the meeting. There hasn't been a reduction in his level of challenging behaviour and his needs.*

SW: *We initially looked at ways for Tom staying at school but also potentially staying at [Children Respite A] for a further year. It would be*

better from my point of view if a young person, all of their transition happened when they left school.

RESPITE: *But in the meeting it was only the transition social work but there was not children and families and I think it was a bit unclear if they would collaborate. Mum told me two weeks later that children and families would not pay anymore after he was 17.*

The decision within the children and families social work team not to support the respite funding for another year can be seen as the first step leading to a change in plans.

Lack of options

There seemed to be only one adult respite service in the local authority able to meet Tom's and his families' needs.

SW: *[Service A] is the only service in the city that can offer night respite for someone with Tom's needs. There was never any doubt about that. It is a service, which only has been open for two years and already is quite jammed up.*

In relation to day services, the family seemed to have two options, the above named Adult Service A and the parents' initial choice Adult Service B.

SW: *There are some other services that could be able to offer support but more outreach support out and about in the community and that is not the environment that Tom necessarily will thrive in, nor did the [family] want Tom to be in. Tom needs a bit more structure and building based service and [Service A and B] both offer that.*

Tom's parents liked Service B, which they had visited previously, but concerns were raised about funding.

SW: *[Service B] is a very, very expensive service and it is outwith the council's budget. I was clear that using some of the respite budget to top up was not a possibility for Tom's family because respite is so important to them. It is a service that has no space at the minute.*

Assessments and budgets

The budget allocated to Tom was identified through the social work assessment, which looked at both Tom's and his parents' needs as carers. The assessment assigns one of four levels of need: critical, substantial, moderate and low. Those with a level of critical or substantial need are eligible for social work services and Tom was identified as having a critical level of need, which informed his budget. Tom's social worker talked to his team leader and the head of disability services

about people's concerns about the decrease in respite under Tom's new budget. Subsequently he was offered a space at Service A for both day and respite provision for this summer. Service A is run by the council and the maximum social work budget equated to a full space at the service.

SW: *For someone with a critical level of need the maximum for day services is 26 214 pounds to be exact. (...) Tom's place at [Service A] is the exact same amount as his day service budget so he can access that service and not have to use any of his respite in order to supplements that placement.*

In my interview with the local authority manager, he explained that local authorities receive money from the government but none of the money is ring-fenced and specifically allocated to learning disability adult services.

MANAGER: *That is their get out of jail, so here is however much money, it is up to you as a local authority to decide how to spend it. But there is a great number of people with challenging behaviour, autism, learning disability who are coming on seeking support and they are the most expensive packages of care.*

Everyone showed an awareness of an overall decrease of funds available to local authorities. Tom's mother said she knew that resources needed to be shared but she also felt that trying to save money by cutting respite provision was short-term thinking. She felt that the risk of creating a crisis, resulting in the need for subsequent accommodation for Tom would be a lot more expensive.

MOTHER: *I think there is this ridiculous scenario of the fact that if we said right let him go to a flat you are talking upwards of 200 000 pounds a year to fund that. Whereas we are quite happy for him to stay at home and go to [Service A] everyday but we still feel we need more respite.*

The manager and social worker had the difficult task to balance the needs of the young person, the family and the budget. Although a case was made to provide a few more respite nights for Tom, it was still less than what he had received before. It seemed that not only lack of funding but the simultaneous lack of services for those with complex needs played a role in the amount of respite available to Tom, as Service A was described as running at capacity.

SW: *At the minute in order to have some kind of throughput in [Service A] and get more people in, they are having to limit that to 24 nights of overnight respite and 11 nights of budget as outreach support just because every year we have more people who need to get into that service. There needs to be a way for them to get in but then obviously that does limit how much people can access.*

Decision made

Social work offered Tom's parents a full day and respite place at Service A, a few weeks after his last review meeting. His parents decided to accept it as (1) it was not clear that a space would be available next year for Tom at Service B, (2) Service B was more expensive, (3) Tom would access one service instead of two (one for day and one for respite provision) and (4) Service A had less holidays than school, which meant the decrease in respite would be smaller than if Tom would have completed his last year at school. Everyone agreed that Tom's parents were central to the decision-making, but Tom's mother herself showed a more complex picture of her role and during all three interviews in 2017 referred to at times feeling unsure about her decision.

MOTHER: *It is this anxiety at the moment of have we done the right things? Is he going to be ok? That is the difficulty.*

Tom's perspective

At the beginning of the new school year, Tom had started to display more self-injurious behaviour at school. He had started to spend more time outside the classroom at local parks or libraries. He seemed to enjoy his time out and about, finding it difficult to return to school for the afternoon. As the year progressed, the school started to voice their concerns about Tom's behaviour in school, feeling that he might need a change.

TEACHER: *At the start of August Tom was showing us that he was preferring to be out of school. His behaviour and anxiety was a lot better when he was out of school.*

People seemed to feel more comfortable with Tom leaving school earlier due to the indication that Tom wanted a change.

MOTHER: *Was there any benefit of him staying at school for another year? Well he is not hugely happy there and he is gonna have to go sooner or later.*

I noted down in my fieldnotes:

I feel this is the first time that Tom has been involved in the decision-making process, and that his behaviour is seen as communication, which allows for his view to be included in the process. (Fieldnotes, case 1, Tom, May 2017)

Usually when I asked about Tom's involvement in the transition, people described that he had limited capacity to understand or make decisions and that it was difficult to involve him.

CLINICAL PSYCHOLOGIST: *I am not sure what his understanding would be of being able to say 'this is where I want to go', his capacity to understand decisions and that which is quite a complex decision.*

TEACHER: *We haven't spoken about it with him. I mean developmental level we are looking at very, very young.*

Interestingly, almost everyone reflected that if Tom could verbalise his preferences, he would want to be at home as much as possible, but people also felt that this was not necessarily in his best interest, nor would his family be able to cope with him being home all the time. Here the complexities of conceptualising choice and interpreting the behaviour of Tom became apparent. Moreover, the interdependence of Tom's needs and the needs of his parents and siblings became apparent.

RESPITE: *When you see him with his family he is very happy and he always says 'home, home, home' and he is saying the names of the brother. I think that if you let him at home all the time that he will be happy as Larry. As a real life, obviously they have a big family, both of them are working so it can't work.*

ADULT SERVICE: *He would choose not to come and to be home all the time. That is not giving him skills and it is not giving him experiences.*

Preparing the practicalities

After his parents accepted the offer at Service A, the school and Service A began to organise the transition. It seemed that one part of the transition process ended here and another one began. The previous section described steps that led to the decision to accept a place at Service A. The following part involved planning the practicalities of the transition. The process seemed to be led mainly by the school, Service A and his respite service, with close communication with Tom's mother. Helping staff at his new service to get to know Tom and to learn how to support him was a big concern for everyone involved, particularly in relation to his self-injurious behaviour.

MOTHER: *I am hoping that they will be able to deal well with his behaviour and yet he will be able to walk around hands free, rather than being held on to all the time. Some schools he has been to their way of coping has*

been to hang on to him at all times. Literally not let go of him and then when he gets home he expects that to continue and that is just not possible for our family situation.

TEACHER: *I want people to see that in a secure environment for them. The first time I saw that happening my stomach just went 'Huuuhh' (...). So it is hard enough being there to support him and also to support staff and manage their feelings and help them see that this is happening, but it is ok.*

For six weeks staff from Service A spent time with Tom at school and his respite and Tom started to visit Service A in the weeks leading up to the transition supported by school staff.

Leaving school and starting adult services

Tom finished school at the beginning of July and people I interviewed just before and after seemed to feel positive about the move. On a number of days Tom displayed high levels of self-injurious behaviour, but everyone felt that the staff were able to support Tom and that on other days he showed signs of settling in well.

ADULT SERVICE: *There was moments where he was smiling and moments where he has been laughing and he has been engaging with staff.*

The next step was to start planning his respite transition and Service A talked with his Clinical Psychologist, Tom's mother and the respite service to develop visual supports and plan 'tea visits'. After Tom had started to attend Service A for both day and respite, I went to see Tom's mother one last time. She described that being home more seemed to have had a positive impact on Tom, while providing the extra care for him was difficult for the family.

MOTHER: *He actually is quite relieved I think now to not be going away as often. From his point of view it is better. Not so much from ours, but he is certainly happy just to go to [Service A] and come back in the afternoon and if you ever say to him 'where are you going?' he always says 'home'. That is obviously where he wants to be.*

Although she described the transition as mostly successful the decrease in respite support continued to worry her. The positive side of the transition, feeling that professionals were supportive and doing their best, and the hardship of caring for Tom and its impact on the family were simultaneously present in people's reflections on the transition process.

Now that his transition into adult services was completed, Tom's transition social worker was going to close the case and pass it on to adult social work, while health professionals from the Clinical Psychology and Psychiatry team would pass on his case to adult health services after his 18th birthday. The transition to adult social care, and losing the involvement of the transition social worker, worried Tom's mother. In adult social care the family would no longer have an allocated social worker, but social workers would get involved as needed.

MOTHER: *If we decide in six months he is not, we are not getting enough respite, where do we go then? Apart from having a nervous breakdown and ending up in [the mental health hospital]?*

Future considerations

Thinking about the future Tom's mother expressed that she was hoping that Tom would continue to live at home and attend Service A.

MOTHER: *I am hoping he can stay there for many years. I am hoping he can stay with us until we are too old and too decrepit to look after him anymore.*

All professionals on the other hand talked about the possibility for Tom to one day move into supported accommodation.

ADULT SERVICE: *I don't know what the future will hold. I would like to think that he will get his own place some time. That's an appropriate thing for a young man.*

TEACHER: *We are setting him up for the foreseeable future with this placement because it would not be good for Tom to be chopping and changing. But five, ten years down the line he outgrows this placement. It might get to that stage that actually his own flat would give him a bit more independence.*

Participants had different views on what the future might hold for Tom within adult life. Differences in views seemed to relate to people either focussing on Tom's consistency in support needs or viewing the transition as a step towards independence and greater autonomy in adulthood. Imagining Tom living away from his family seemed to worry his mother and notably the question of what would happen once his parents could not advocate on his behalf any longer was not explored by anyone except his mother.

MOTHER: *What will happen when we are dead is my main concern. Who will look after him? Will he be happy? Will he have a fulfilled life? (...) But*

you have to put it into perspective and think we do what we can do, at the time. We keep doing what we can until we can't do it anymore.

6.1.1.1.3 Concluding remarks

The exploration of different perspectives in Tom's case revealed differences in people's knowledge about the transition process. Except the transition social worker and local authority manager, most participants were unsure about the transition process in relation to responsibilities and timeframes and this seemed to elicit stress and anxiety for his mother. For example, once the formal process had started, his mother was unsure how the transition would affect the involvement of health professionals, which was explained to her at a later stage. Similarly, the change to adult social work was unclear for her in the second interview, and she expressed worries of soon having no one to turn to. Procedures had been explained to her towards the end of the transition and she did have more information in the last interview. Having all the relevant information as early as possible was her main recommendation to improve practice.

MOTHER: *I think there should be a booklet out there. With an idiots guide (...) really simple.*

Tom and his family had had a close-knit support network during his years in children services and his mother had felt supported by professionals.

MOTHER: *I think we have been lucky. (...) I think people are well aware of how hard it is to look after him and I also think people like Tom. They want him to do well so people have got very involved with his case which is great.*

While his mother had experienced the practical transition from school to Service A as positive, she was anxious about the decrease in support and the loss of familiar relationships and networks in the life of Tom.

6.1.1.2 Emma

In the following I will present the transition journey of Emma. Emma and her family were in the middle of the transition process when I got involved. Her transition had started well, and the family had been able to get a place at their chosen day service, where they had wanted Emma to go for a long time. Yet, throughout the process tensions grew between Emma's parents and social work. Emma's respite transition had not gone well, and the family felt that they were not seen as a priority. The stress of the transition had taken a toll on the health of both parents. They experienced the process as a fight and were worried about Emma being caught in the middle.

6.1.1.2.1 Case description and timeline

Emma and her family lived in the same local authority than Tom and she visited the same school. She was described by everyone as a pleasant and easy-going young woman but at home her need for activity, routine and her difficulties to communicate could result in stress for her parents and they felt that Emma's needs often dominated their lives. I visited Emma twice, once at school and after the transition, at her day service. I noticed that she liked to be engaged but was reliant on prompts and how she interacted with her environment through her senses, particularly through touch, vision and proprioception.

OBSERVATION: *Emma sits on my right. It is snack time. Her teacher asks her if she would like some more. Emma points to the Weetabix packet. 'Ok' he says. Emma does not move. She looks across the table. Her teacher says: 'Ok, what do you need for it?' He moves the tray with the cereal packets, bowls, milk and cutlery closer to Emma. She looks at him and he nods and only then does she take the cereal packet. (...) Later on Emma is standing at the end of the classroom. Facing the back wall she blows bubbles and watches them disappear one after the other. Then she blows more bubbles. The bubbles drop slowly to the floor and stick to the ground. Emma watches how they drop and burst. A few won't burst. She touches the few ones left with her foot. They burst. Then she blows bubbles again. I can only see her back. There is a static rhythm to the activity. She looks back at the bubbles, she makes a 'happy' noise "Aaahhahhhahhh" and rocks back and forth with her whole body. She shakes her hand in the air. When she blows bubbles she reaches out with her left hand to catch some of them. They burst on her skin. (observation vignette, classroom, April 2017)*

The following table will give an overview of Emma's transition journey.

Figure 18: Transition journey Emma

2015	Family starts to find out about adult services within local area	Emma: is seventeen years old and in her last year of school. She enjoys the company of others and to be part of busy environments engaging in crafts and joining social dance activities. Emma likes singing, music and one of her favourite activities is to blow bubbles. Emma has a diagnosis of autism and severe intellectual disabilities. She is physically very able but depends on other people to prompt her. She can say some words and sentences and is able to repeat words but mainly communicates through signing, picture exchange and through her behaviour Emma's parents feel that they are approaching an age where they would like Emma to start living outside of the family home. This has been discussed with her transition social worker but does not seem to be an option at present due to lack of provision. Emma already experienced a transition to adult respite services earlier in the year and the process did not go smoothly resulting in tension between her parents and social work. Exploring day service options, her parents would like Emma to go to a local day service that offers workshop-based activities. Its fees are higher than the local authority run day services. To make it possible to fund the day service for five days, her respite allocation is reduced. While the family thought initially they could cope with it, they are finding it increasingly difficult to manage with less respite once Emma leaves school. The wish for supported accommodation remains the main concern for her family.
Aug 2016	Transition social worker (SW) allocated	
Sept 2016	First meeting with parents. Focus on supported accommodation	
Oct 2016	- SW told by management accommodation not feasible - Parents feel Emma might be too young for accommodation	
Nov 2016	Review meeting at school. Service A supported as day service	
Dec 2016	Children respite stops. No handover to adult respite	
Jan 2017	- SW assessment completed. Adult respite service identified - Application to Day Service A through SW	
Feb 2017	- Start adult respite service - No transport to respite provided. Parents refuse to provide it - Parents and SW file complaints - Transport arranged through school and later SW	
March 2017	Mother and Emma meet Day service A manager	
April 2017	- Day service A and SW work out funding for 5 day service - Social work ask parents to contribute to 5 day service - Parents agree to reduction of respite to fund five days - Place at Day service A confirmed for summer - Day service A and school exchange information	
May 2017	- Emma starts weekly trails at Day service A supported by school - Speech and language offer joint support to Day service A	
June 2017	- Funding for transport to Day service A in question - Transport sorted. Emma shares taxi with other young person	
July 2017	Emma finishes school and starts at Day service A	
Sept 2017	- Review meeting at Day service. Placement positive - Parents voice continued wish for supported accommodation	
Oct 2017	Transition to adult SW	

The timeline shows a gap between Emma's parents starting to plan and think about the transition in 2015 and the involvement of the transition social worker in August 2016. The time spent preparing Emma and supporting her to get to know the day service comprised approximately three months, starting in April 2017, while decisions around the funding package were sorted only days before her start at the adult service in July 2017.

6.1.1.2.2 Narrative conversation: Transition collage

I interviewed seven people who were involved in Emma's case. Everyone, except the local authority manager, had direct contact with the family. Excerpts used from the local authority manager refer to the same interview as in Tom's case.

Table 28: Introducing the actors – Emma's case

Actors	Role description
MOTHER and FATHER	Emma's parents are in their late 50s and Emma's main carers. Emma's mother works within the health care sector and her father within education.
CLASS TEACHER	Her teacher started to work at Emma's school three years ago and took over her class last year.
TRANSITION SOCIAL WORKER (SW)	She was allocated to Emma's case in summer 2016. She has met Emma regularly in different settings. Once the transition is completed her involvement will stop.
ADULT DAY SERVICE MANAGER (DAY SERVICE)	He is the manager of Emma's future adult day service, a third sector run organisation offering workshops and art and craft activities for adults with intellectual disabilities.
SPEECH AND LANGUAGE THERAPIST	She is usually based at a different school within the local authority and only got involved in supporting Emma's transition

	and assessing her communication four months before the end of school.
LOCAL AUTHORITY DISABILITY MANAGER (MANAGER)	Within the authority's health and social care partnership, he is responsible for people with learning and physical disabilities. He manages the social work transition team, and agrees allocated budgets.

Finding a meaningful service for Emma

Emma's mother started to think about the transition in 2015. It was important for Emma's parents to find a service for Emma they could trust and they felt that the local authority run services were not suitable for Emma. They viewed the transition not only as a change for Emma but also as a change for themselves and their roles as carers. A transition social worker met Emma's family for an initial conversation at the beginning of the school year in 2016.

MOTHER: *I have always been bothered about it [the transition]. I was actually pre-armed before [the social worker] came and she told me of the places that I would like to go and visit and all the rest of it and when I said in a very nice way, not in a bad way, where she wouldn't be going (...) I think it is maybe because we are getting older, I mean, I know it is not that old, 57 it is not old, but I don't know if we could take another 20 years of it.*

SW: *She knew what was out there definitely, so from last November we've kind of known where we are going.*

Emma was described as a very biddable young woman and relatively 'easy', yet at home her behaviour could be more challenging.

MOTHER: *She is given us a lot of jib the now about walking, she is just ruining it. I mean she is really pushing it, that she does not want to go and then she is 17 so I sometimes feel well when she was younger she would just have done it.*

SW: *I think for some people when it comes to adult services I think, think, wow we have done it (...) and the facts are that as long as Emma lives with her family she, her needs will be the same if sometimes maybe a bit more.*

Supported accommodation

Both Emma's parents and her social worker felt that Emma's behaviour at home indicated that she enjoyed being outside her family home. In my conversations with her mother it struck me that she was able to see Emma's behaviour as communication, instead of focussing on the difficulties she was experiencing with Emma at home.

MOTHER: *I said I would love for Emma to go into an own accommodation because she really needs that. She loves being out, she loves being with people.*

SW: *That is a discussion that I had the first day that I met them. (...) So I came and brought that back to the office and got in touch with the housing support and strategy manager.*

The social worker was told by her management that supported accommodation would not be feasible at this stage, as other cases had priority.

SW: *He was just like there is certainly at the moment there is six young people that are in residential schools all around Scotland that are waiting for accommodation.*

MANAGER: *For a small number of individuals where the family home situation has broken down, they may already not be living in the family home, they might be in an out-of-the-authority school placement and at the end of their educational support then they would come back [to the local authority].*

MOTHER: *They have got a lot of children up in [out-of-area placements] (...). They can't afford to keep them up there, so they bring them back and they get the accommodation first. Because their parents refusing to take them back and I can understand that. I can understand that fully. So that was fine. I said well she'll have to get five days whatever it is she is doing.*

Emma's parents accepted that accommodation might not be an option now and in the first and second interview Emma's mother also wondered if Emma was still too young to move out. During the social work assessment, Emma was assessed as having a critical level of need, making the maximal funding for day services available to her. Additionally, the assessment highlighted the families' wish for accommodation in the near future.

Finding a Day Service

Her parents felt that Emma would be happiest at a service where she could have peers and the chance to be involved in group activities. Her parents ruled out two local authority run services catering for young people with challenging behaviour

and complex medical needs and did not want a home-based outreach service. Thus, it seemed that the family had a choice between three third sector day services. From the three services, her parents strongly favoured Day Service A, where adults worked together in small workshops, such as pottery, cooking or gardening.

MOTHER: *I said to [Emma's father] I think you should come and see this place because I just have got this feeling when I am there and the people are really nice.*

DAY SERVICE: *People are encouraged to engage in work that has a meaning for them and a meaning for the community, that within the building.*

Day Service A was supported as a choice by everyone at a review meeting in November, which was the only review meeting during the transition process where all professionals came together. The service's fees were higher than the local authority run services and concerns were raised if it would match Emma's budget.

SW: *I remember [Day Service A] being mentioned from day one and me thinking 'God those services are usually 34 thousand. How is this going to manage?'*

Respite transition crisis

Emma's transition from her children respite to an adult respite service occurred at the end of 2016. Emma had her last day in December and there were around six weeks where the family did not receive any respite. There was no period where Emma started to visit the new service and where staff could get to know her. Her parents were not happy with the service that was chosen by the local authority. There was little communication about the respite transition and her parents felt that they were told about decisions without giving them other options. The move to adult respite resulted only in a slight reduction in respite days for Emma, because differently to Tom, Emma did not receive the maximum amount of respite days in children services.

MOTHER: *I was worried about, I mean she is only got one more week in her children respite. Where is she going to go? And all the rest and she will go to [Adult Respite A]. I didn't actually want her to go to [Adult Respite A] because I think it is like a secure unit.*

SW: *The thing that let Emma down was (...) the respite. (...) So it finished at Christmas time then there was a few months until something was set up*

and that was a big disappointment to the family because it should have been more seamless.

Decisions were made based on available resources and common practice instead of considering Emma's individual needs and preferences. The social worker reflected that she tried to argue for a different service, which she felt would have been more suitable, but that there did not seem to be room for flexibility in the allocation process.

SW: *My boss and there is another five people around the table, and they look at the assessments and they look at the memo (...) and they decide what would be the most appropriate resource. (...) I am not entirely happy because I feel like [Adult Respite A] is generally for mostly autistic specific but it is really for challenging people. Emma she does not really belong to that category (...). But because (...) I say [her overall level of need identified in the social work assessment] is critical then there is this sort of 'Oh you are saying she is critical so it wouldn't be fair to have her in a group with shared support'.*

Similarly, her parents felt that there was little flexibility when it came to arranging transport for Emma to and from the respite service. Within the local authority the transport policy had recently changed and parents had been asked to provide transport themselves. Emma's parents felt unable to provide transport due to their work commitments.

FATHER: *We are expected to (...) go down, pick her up from school, take her down and then go back in the morning to pick her up from the respite unit and take back up to school. Well I am working at that time in the morning any way. And this is supposed to be respite. The other view was ask the bus that takes all the children home, they go down that way anyway just to drop her off and they gave us a lot of hassle, about how they need to do a risk assessment and the fact that she is an adult now, but she is still in school and she has never had any problems on the bus at any time in the past.*

Her parents decided that they would not provide transport themselves, which led to tensions with the social work department. Her parents decided to fight their point but were concerned that Emma could be caught in the middle.

MOTHER: *I am prepared to support Emma, but I am not prepared to have them take absolutely everything off us. (...) I can't, I am finding it hard to express myself because now I am just going to pack her bags. You know what I mean? I am going to give her up. (...) And we are prepared to do it, but I am not, if we ever have to do it, I know that we never get over it.*

SW: *There is words that are very common: 'I put them into care and then it costs the council three or four or five times more'. And I can only say*

that would be true but is that what you want to do? And it generally is not. It is just for families and people who just start now, it is very difficult. I mean there did seem to be more of a pot of money that was more readily available, but the money is not there anymore.

Both her parents and social work filed complaints against each other. In the end social work agreed to arrange and fund transport for Emma.

SW: *I had a great start with her mum and dad and then the respite, and then the respite transport, which they challenged the whole system, which I think is fantastic. And they got a result and it is actually now being looked at for everybody. Because I don't know how other families were managing. They were just quietly getting on with it.*

Once Emma started at the respite service in the beginning of 2017 her parents felt more positive about it. Her social worker continued to speak about a possible move to another service, but nothing happened during my involvement with the family.

Day service application and funding negotiations

In the beginning of the year 2017 Emma's family applied for a place at Day Service A and the service started their own assessment.

DAY SERVICE MANAGER: *We set up an interview so I met with [X], the person who is the kind of admissions coordinator. So the two of us met with Emma and her mum back in March I think. (...) Emma was present the whole time. She kind of came in and out of the conversation, walked around the room, had a bit of a look around the room (...). She seemed quite kind of calm and happy with what was going on and what we were talking about and her mum talked about how she needed Emma to get a full time service.*

To fund five days at Day Service A Emma's parents needed to agree to a reduction in their respite allocation and the service needed to agree to have Emma as part of a group for some of the time.

SW: *Sometimes what I try and guide the families to do is maybe have three days at [Day service A] and then two with a bit outreach where it is sixteen pounds as opposed to twenty-two pounds an hour. We are meant to evidence good value for money. But if you got a family that say I only want [Day Service A], that is not for me to say that can't happen.*

Because Emma's parents had accepted that supported accommodation would not be an option, her parents and their social worker had hoped that the family would get more support to look after Emma at home.

SW: *What disappointed me was that I actually went back to [Emma's parents] and said it is not going to happen overnight. It is going to take a long time but you are going to get a really kind of robust service that will take the stress off and that did not happen of course. Emma just got the same as everybody else, so it can be quite humiliating, and it is not great at times.*

To fund the five days, Emma's parents agreed to a reduction in respite to pay for it. After reading over the summary of our interviews, Emma's mother asked me to add the following statement:

MOTHER: *We only get 24 nights, the other 11 nights where taken off us to pay for the 5th day at [Day Service A]. I thought this would be ok but I am exhausted. Two nights a month is not good, but I would not like it if Emma didn't have full time, as that what she needs and that's what helps her and in the long run with good behaviour. Emma will continue to improve hence this will save the council money in the long run.*

Preparing the transition

Once the funding was agreed Emma's school and Day Service A started to plan the move for July 2017. At a later stage Speech and Language Therapy became involved to support staff that would work with Emma at the day service.

DAY SERVICE: *She came for one morning, then she came for a day and then she's come for more days. (...) She has a high level of support needs, so it remains to be seen how independent she is able to be in the workshop groups. (...) People need time to adjust to the building environment, the change, the new routines, the new rhythms. (...) What we hope is that over a period of time she will begin to feel a sense of belonging. Belonging is what we are hoping for.*

Leaving school and continued wish for supported accommodation

Although both parents were happy that a five-day placement had been agreed, they continued to want supported accommodation and approached a provider offering shared flats but then changed their minds as they realised that this could mean losing Emma's place at Day Service A.

SW: *In her own rights as a young woman, an adult, she is entitled to supported accommodation. But then she would lose her day service. See, about three or four years ago, maybe slightly a bit more (...) they could have their flat and they could go to a service but nobody gets now and I think that really, really worried [Emma's mother]. So you are solely dependent on that team being enthusiastic, creative.*

MOTHER: *I was quite shocked when she said if she does get somewhere to go now, she will not get [Day Service A] and we really couldn't have that.*

Emma had her last week in school and transport to her day service still hadn't been arranged but was eventually sorted out. There was a small celebration for those leaving at the school and after the first weeks at her new day service Emma was described as settling in well.

MOTHER: *I think she has gone for it.*

Plans about the long-term future

The Review meeting at Day service A in the end of September 2017 described the placement as a success. Emma's parents stated that for the near future they would like her to move out of the family home and keep her day placement at the service.

MOTHER: *The worst thing that I get is conflicting stories where if Emma does get a flat we take away the money for [Day service A]. And then there is someone else who actually got [Day service A] and she lives in a flat that is owned by [Day service A]. And this all came out at the meeting and I find that really frustrating, because I want her to be somewhere, I know she is well looked after.*

Reflecting on the possibility of supported accommodation, actors felt that living with other young people would suit Emma better than living by herself. Emma's family decided to put her name on a waiting list for an organisation that provided shared living within a rural setting and had a connection to Day Service A

MOTHER: *I want her to be somewhere that is like [Day service A] and they have a place (...) about an hour away. (...) We have to put her name down for that. That's what [the social worker] said to me. (...) She is quite profoundly autistic and cannae talk except the odd words and that and but she does need to be stimulated that is the most important thing I think.*

After the meeting Emma's social worker stopped her involvement and the case was passed on to adult social work.

6.1.1.2.3 Concluding remarks

Emma's transition to Day Service A was described as successful and she was described as thriving and learning new tasks. Yet, it had come at the price of a reduction in respite support. Both parents described feeling stressed by the organisational process of the transition as well as caring for Emma at home, illustrating how the need for adequate support was vital for the family to continue to support Emma to access activities and continue to grow and be happy. For her

parents past experiences of looking after Emma as a child were mixed with their present experience of stress and anxiety during the transition.

MOTHER: *I don't think there is a more stressful time for us although looking back on it when I am called to remember what it was like in the past, as we said talking about the door and the smearing and putting up with that all these years, for years and years that went on, and a lot of screaming. I remember the days the things that were completely ruined because we didn't know what was wrong with her, what was up with her, why she was you know and then she turned into this lovely wee girl, young woman, you know what I mean.*

Her parents worried about the long-term future and wanted to find a place for Emma they could trust to care about her and support her.

MOTHER: *This is all I think about it is all that consumes me well the last thing I think at night is settling her, hoping that no one hurts her.*

FATHER: *She eventually will have to, we are going to die at some stage and if you, we are not looking forward to that bit but*

MOTHER: *No*

FATHER: *The point is she is going to have to be in a place that wants her and where we are satisfied that she is going to be looked after properly.*

6.1.1.3 Peter

In the following I will present the transition journey of Peter. His transition journey was different in a number of ways. His family lived in a rural area of Scotland, which limited the number of services available to Peter and resulted in an out-of-area placement for him. Additionally, he had transitioned from a residential school to a residential adult service for young adults one year previously. Thus, throughout interviews participants reflected on a process that had taken place in the past.

6.1.1.3.1 Case description and timeline

Peter had moved from a residential school to a residential adult service in the summer of 2016, before the start of my study in the spring of 2017. The people I spoke to described him as a warm and sensitive young man who could be anxious to get things wrong. I got a similar impression when I met Peter at his adult service and it struck me how Peter related to his environment through his senses such as vision, touch and movement.

OBSERVATION: *After breakfast Peter is in the dining room with a member of staff, who I will call Lisa, and they are preparing the room for lunch. Lisa opens the door to a cupboard with plates and cutlery. She points to a picture on the door of plates and asks Peter to take the plates and set the tables. 'You can do it', she says. Peter smiles at her but does not move. 'Take the plates, please', she repeats and points at the plates. Peter then moves his arm towards the plate while looking at Lisa. She nods and says 'yes' and he takes one plate, walks to one of the tables and places the plate next to one of the napkins, which have been laid out. He goes back to Lisa and takes a second plate. Throughout he continues to look at her and she directs him with nodding and pointing. After three more runs she leaves the room and Peter continues alone. He places each plate next to a napkin. He smiles and hums, it is a repetitive sound and quite loud. You can hear it in the next room. I am sitting in a corner at the back of the room. At some point he notices me. He looks at me, slows down and then continues when I look away. He has finished with the plates. He returns to the open cupboard where he stands swaying from side to side humming. He closes one eye and looks at the ground. He bends forward and moves his face close to the cupboard door squinting his eyes. He stands in front of the door for about three minutes, swaying, looking across the room, then he pauses and looks at me. Maybe he is looking for a prompt? Then Lisa comes into the room again and asks him to continue with the glasses. He has been setting the tables for lunch for almost a year now. (Observation vignette at group home within residential community, case 3, Peter, September 2017)*

Figure 19: Transition journey Peter

Mid 2013	• Family bring up transition in review meetings • Parents visit different adult services	Peter: is nineteen years old at the start of the study. He is a very active young man and enjoys climbing, cycling and going for hikes. He enjoys food, to relax and listen to music. He has a diagnosis of autism and severe intellectual disabilities. He has only limited speech and is mostly nonverbal, communicating through signs and picture exchange. He is able to repeat phrases and will often repeat sentences but it is unclear how well Peter is able to comprehend what is said to him. Peter is physically very able but needs other people to prompt him for most day-to-day activities. He has a close relationship to his brother who also has a diagnosis of autism and severe intellectual disabilities. Peter's family live in a rural area of Scotland. When the family were looking for a secondary school placement for their sons, they became aware of a school offering residential placements; Peter and his brother went to live there during term time. The family were very happy with the residential community setting, and want a similar placement for Peter and his brother within adult services. The primary concern for Peter's parents is finding somewhere where their two sons can continue to live together. After one service rescinds their initial offer of two placements, his parents apply to a residential community for young adults three hours drive away; a place is offered to both boys. The adult community offers placements for young adults up to the age of 25 and his mother is anticipating to start planning for the next transition very soon.
Early 2014	• Parents make application to residential adult service A one hour drive away. Brothers names are placed on waiting list • Social work supports application and begins assessment	
End 2014	• Service A retract their offer of two placements for summer 2016 • Parents visit different adult services throughout Scotland • Parents prefer residential young adult service B 3 hours away	
Sept 2015	• Adult social worker becomes involved and resumes assessment • Service B admission team visit Peter and his brother at school • Meeting at school with parents and service B • Luke moves into his flat • Day Service A move into new building	
Oct 2015	• Two 40-week placements offered by service B	
Early 2016	• School, parents and service B start to exchange information	
May 2016	• SW funding agreed for both placements	
June 2016	• Peter and his brother visit service B supported by school and • Parents and service B key staff exchange information and	
Aug 2016	• Peter and his brother move to service B	

During Peter's transition events were spread out over three years, 2013-2016, with an increase in activity around three main events: (1) the first application to an adult service more than two years before the end of school in early 2014; (2) his parents needing to look for options again after the first placement falls through at the end of 2014; and (3) the second application to a second adult service in 2015. There was no transition social work team in Peter's local authority. In his case the children and family social worker handed the case to an adult social worker and both worked together during Peter's last year of school. Interestingly, although his placement at the second adult service had been confirmed almost a year before the end of school, the phase of preparing Peter only started 12 weeks before his move in the summer of 2016. The adult service reflected that it was difficult to support the process earlier as knowing about the practicalities of a placement often interlinks with existing service users first needing to move on. Although a place could be confirmed in general, it was difficult to identify the details of which house and which staff in advance.

ADMISSION SERVICE B: *The actual knitty-gritty however can often be relatively and I say last minute. I mean usually you would get that organised say in June and someone would start in August. Because we also need to know where our vacancies are (...). The challenges with being so proactive is not necessarily completely helpful because you don't know whether you are going to have a vacancy for that person and then starting off early isn't necessarily going to secure a placement.*

6.1.1.3.2 Narrative conversation: Transition collage

I interviewed seven people who were involved in Peter's transition. During my interview with the adult service admission team two professionals were present.

Table 29: Introducing the actors – Peter's case

Actors	Role description
MOTHER	Peter's mother and father are his welfare guardians. His mother used to be a teacher and she did a home therapy program with both her sons after their diagnosis age 3 for a number of years. Peter's father works within the corporate world.

ADULT SOCIAL WORKER (SW)	Peter's adult social worker got involved around one year before the end of school. This is her first social work job. When she got involved contact to adult community B had already been made. She completed the outcome assessment with the family and agreed the funding of the placement. She has met Peter at home, at his school and in his new placement on a few occasions. At the end of my research she stopped her involvement and Peter now has a new adult social worker.
ADULT SERVICE SENIOR MEMBER (ADULT SERVICE)	She manages the house Peter lives in and lives with her family within the community herself. She supervises Peter's key-workers and communicates closely with his mother.
ADULT SERVICE ADMISSIONS TEAM (ADMISSION 1 AND 2)	Both professionals are responsible for admissions to the service but have other responsibilities within the organisation in relation to care management and day service provision. They have worked in the adult community for over 20 years.
TEACHER	Peter's teacher took over the class two years before graduation. He taught both Peter and his brother. He also lived with his family in the same house where Peter lived during his time at the school.
LOCAL AUTHORITY MANAGER (MANAGER)	He is part of the management team for mental health and learning disability. His role includes

	supervising social workers, strategic planning, operationalisation of service design and service development in partnership with health services.

Early school experiences

Having two children with high support needs was challenging for Peter's family living in a rural area. Peter's mother described how her experiences of finding a nursery and primary school was difficult and experiences made during the primary school years were particularly upsetting for the family.

MOTHER: *That time was as very much about inclusion but being in a rural community it was difficult for nurseries and schools to understand exactly what that inclusion process meant. Hence there were barriers already about 'Oh what are you going to do with these children? We cannot in a small rural setting cope particularly with two of the same diagnosis.' (...) It was very distressing because we were led to believe in the meetings that the boys would access mainstream primary classes more than they would be in the unit on their own. And the opposite happened so the placement deteriorated [Peter's brother] and Peter, particularly Peter who was the more sensitive of the two, his behaviour did show some distressing signs. He was very distressed when he came home, he was not sleeping very well. He was not eating very well. (...) The relationship broke down quite badly and in the end there was no really easy option but we had to take the boys out of that placement for their own safety basically.*

The family sought legal support to find a more suitable environment for both boys and for their secondary school both brothers moved to a residential school (School A).

MOTHER: *I just knew that that would be the perfect environment. (...) We had been to see some respite places over the years where there were lots of locks on the doors and things were locked away and there were no carpets on the floor (...) walking into 'school A' when you see beautiful paintings and just this beautiful feeling of serenity we just knew that Peter would thrive and he did.*

Finding the right environment for both young men

Peter's mother felt that Peter needed to be in an environment where he would feel safe. Similarly, others described Peter as anxious in unfamiliar environments.

MOTHER: *If he was outside the home or the school, where he feels safe, he would not be able to communicate. He has no sense of danger so again that puts him in a high risk outside in the community on his own.*

SW: *He is very anxious about doing things wrong almost and he is not, he doesn't feel confident to make his wishes and needs known right away.*

His mother was very positive about the model of School A where between four to six young people and some of the staff lived together in houses. His mother felt that his school placement had given Peter the possibility to grow and develop and that this was partly because he was able to live in a different house setting than his brother. People described how Peter tended to stand in the shadow of his brother and being able to live in the same setting but in a different house seemed to have benefitted him.

TEACHER: *His brother was always the dominating one (...) before he came here, but also in the beginning still here.*

MOTHER: *He developed his own interests, he had a lot of reassurance and support (...) and then that has continued at [his adult placement] and he has had a different house setting than his brother.*

First search

After their negative experiences during the transition from nursery to primary school, Peter's parents started to plan the transition to adult services early on.

MOTHER: *Because of our experience when the boys were younger, we knew in order for transitions to go smoothly at a senior level we would have to start the process a lot earlier and we did. I mean I can look back at the review notes and I think I was mentioning transition three years before the boys left.*

His parents identified an adult service similar to his school, a ninety-minutes-drive away, and put both brothers' names on the waiting list two and a half years before the end of school. This was supported by social work. However, six months later the service closed their waiting list.

MOTHER: *It wasn't a reflection on the boys it was the fact that they had taken a lot of people the year before and that they decided for things to calm down before they offered any more places.*

Second search

Peter's mother started to look at places again throughout Scotland and favoured a residential service for young adults (Service B), around three-hours-drive away from the family home, which would result in an out of area placement. A lack of adult provision on a local level was mentioned across interviews.

SW: *We just didn't have anything on the local level that was really suitable or appropriate.*

MOTHER: *As I was going round all the different places each place was very much saying we have a waiting list this long (stretches out arms). You will be so lucky to get one place, you will be extremely lucky to get two places and that was our aim.*

MANAGER: *You will find young adults from Scotland placed in residential placements all over the country from Aberdeen, to North Wales to the South of England. And that is probably in the history for the last 30, 40 years and when the NHS long term hospitals closed down, in a sense we replaced that for an awful lot of people at the high dependency end, very high dependency, with residential placements. (...) Certainly there is a direction of travel now to be saying high dependency placements you should be able to provide and support high dependency placements in the local area (...). I think providers can still be quite reluctant to go down that way. For real high dependency you need a very, very specialised kind of resource and as I say that is why you have difficulties.*

Peter's mother felt that a young adult place might be better for Peter and his brother at this stage in their lives.

MOTHER: *There was an energy and lots of activities and that's when you just thought yes [Peter's brother] and Peter still have an opportunity to be young people in a young person's place.*

Overall, Peter's mother felt that the local authority was supportive throughout the process and that the family was able to choose the service they wanted. Social work encouraged the family to consider a service that supported people in single tenancies in their local community, but his mother felt that this would not be in Peter's best interest.

MOTHER: *I didn't want them being part of a fragmented group that only met occasionally to go to the cinema or bowling because autism is a condition, it is natural to withdraw and being in a flat on their own would give them every opportunity to withdraw. (...) I think he would feel totally lost. So we weighted up all the pros and cons and went to talk that through with our transitions officer that was [his children social worker]*

and then [his adult social worker] came on board and was able to understand where we were coming from.

An application was made to Service B who started their assessment in the end of summer 2015 and confirmed a place for both Peter and his brother in October that year.

ADMISSION COORDINATOR 2: *I think what stands out quite strikingly in that scenario was that they were so far in advance of when they were due to leave which was quite unusually actually.*

Funding the out-of-area placement

There did not seem to be a problem to get the funding for the residential out-of-area placement agreed. The residential placement was described as being more cost effective than 24-hour care in a flat. The possibility for Peter and his brother to return back home was not an option that was discussed.

MOTHER: *When we then looked at the costing of a residential placement from a cost-effective point of view it was going to be a really good cost-effective option.*

SW: *It would be unreasonable and also unsustainable for him and his brother to return home with a tremendous package of care if you like.*

Initially his parents asked for a 42-week placement, hoping it would increase the chances of getting the package accepted and because Peter's parents felt that coming home regularly was important for him. Due to strained capacities at Service B Peter started on a 40-week placement but this changed to a 42-week placement at the end of his first year at Service B. The family experienced a number of social work changes throughout the transition, and although this caused Peter's mother stress, it did not negatively impact on the transition. People described how the family was driving the process and information was passed on between social workers.

MOTHER: *The transition could have been a nightmare, because as I say our communication was very open and people did come and go, as I say we dealt with about four different people in the transition.*

TEACHER: *[Peter's parents] I think know their way around, they know how to get their point across, which again is not everyone's ability.*

Peter's involvement

When I asked about Peter's involvement people spoke about a conscious effort to involve him, for example by supporting him to attend the review meetings held at his school. At the same time people described that it was difficult to really know how much he understood and that it required people to know about his responses to different settings to make sure that decisions reflected his wishes.

MOTHER: *He was just happy to sit in reviews and smile at everybody and just by I think people observing him, sitting calmly and without distress and everybody could see that he was in a happy place and felt good in himself because I think we can all tell can't we.*

Admission 2: *I guess Peter was involved from the point of view expressing how he was finding things at [School A] because of the basis of mum wanting him to come here was because of her experience of the school.*

Move from school to service B

Before the move in the summer of 2015 Peter and his brother visited Service B and the adult service involved Peter's parents in setting up his room and daily timetables.

ADULT SERVICE: *We really involved them because we wanted them to decide what was important for him. His music it is important. He has his CDs, his books and his photos.*

Additionally, his teacher started to introduce work-based activities that were offered at Service B during Peter's last year of school.

TEACHER: *In the last two years he really did just these sorts of things. There was gardening, there were craft activities. I mean there was a bit around communication of course still, literacy and numeracy, but really in a practical context.*

People described that Peter settled in quickly and seemed happy. Although the distance was difficult for his mother, she felt involved and there seemed to be good communication between Service B and Peter's mum.

MOTHER: *I mean I get pictures on skype and they are always doing wonderful things and stuff. And I think yes I mean Peter can't come home and tell me hey mum I climbed a mountain today or drove my bike around the facilities but he is just a smiler and in fact his house produced a book which I need to add to all his others and it is just a photographic testimony of how, what a great year he has had.*

Life at Service B

At Service B Peter shared a house with five other young people and six members of staff who also lived in the house. During the week Peter worked in the wood workshop, pottery, the garden and kitchen, which were all based within the community setting. In his free time he enjoyed spending time in his room or common spaces, to go swimming, visit local cafes or go hiking. His adult service described that they were trying to support Peter to be more independent and that it helped him to have consistent routines and familiar environments.

ADULT SERVICE: *There is definitely development. What we have to be really aware of is, if he has a change of person, so he is with somebody else, that easily his achievements it can easily regress as well.*

SW: *Peter has a certain amount of flexibility to him, but he does still need to know what is happening, what is expected of him and that has to be presented in a way that he can understand. So there is a lot of work that goes into that part and then I suppose it is only through that, can you start to learn skills around independence and being more confident and trying to make his needs and wishes known.*

MOTHER: *I just think with lots of reassurance, with a great support network around him he developed into a really self-assured, confident, well-balanced considering the challenges he faces every day because of his autism.*

Considering the future: The next transition

His placement at Service B was going to stop once Peter turned 25 and his mother was already anticipating the next transition. Reflecting on Peter's future his mother continued to want a similar residential community place for Peter.

MOTHER: *I think that living in a flat in a city centre will not suit Peter or his brother. They are both still very vulnerable young people and I think they need to be with individuals that are trained and they can trust and it is reciprocal, the boys continue to be treated with dignity and respect despite their limitations.*

For his social worker it was a main concern to bring Peter back closer to his local authority.

SW: *There will be a lot of planning involved there is no way round that so you have to make sure we are still able to meet his needs when bringing him back.*

6.1.1.3.3 Concluding remarks

Peter's transition included many positives. His mother had experienced both his residential placements as supportive and she felt that she had been closely involved in the transition. This led her to feel positive about Peter's possibilities to develop and thrive within adulthood.

MOTHER: *We feel as we get older he will still continue to find things that we never thought was possible, so for example we were told when he was three years of age he would never ride a bike, now he can ride a bike probably further than his brother, probably further than myself and my husband included. So he continues to surprise us with the potential that he has. So I think he can continue to do that, continue to thrive in the community that believes in him and doesn't see the label of autism.*

Participants noted that Peter's transition was a positive example within a challenging context. Referring to other cases all participants spoke about a system that was not always able to meet people's needs due to financial constraints in adult services and lack of appropriate services.

TEACHER: *Everything seemed to fall much more to place than it often is with many others where two weeks before they leave you still don't know or sometimes even nothing is organised and then you end up in a situation where they have to stay longer in school because there simply is nothing and at home it also wouldn't work.*

MOTHER: *We had had no problems at all, and we were talking to a group, within a group of people who were having very bad experiences like literally their child was turning 18 and all funding stopped.*

6.1.1.4 Study one – summary and reflection

The examination of the three transition journeys revealed positive practices, as well as barriers and concerns. The move to their new adult service setting went well for all young people. Relationships between professionals and families were largely experienced as supportive and there was evidence that young people and their support staff had formed, or where in the process of forming, close relationships. Barriers and difficulties were largely located within the organisational realm. Focussing on the three transitions as processes helped me to map where key decisions were made and what influenced them. The timelines showed how funding and availability of services influenced the timing of transitions. For example, Tom left school one year earlier than had been anticipated and in Peter's case although his placement had been agreed almost a year in advance, details about his exact placement at his present adult service

could only be confirmed three months before the move, once current service-users were identified as 'moving on'. Most notably, it was evident that available resources played a central role in identifying service providers and the amount of support available to families.

6.1.2 Study two: Three transition journeys within adult services

Study two builds on study one to explore what happens within adulthood, once the transition to adult services has been made. Study two followed the same design as study one and will present case studies of the transitions of Luke, Lisa and Ben. The three adults were of different ages (25, 28, 39) and therefore at different stages in their lives. The focus of this study was on transitions out of the family home and into supported accommodation, but across the cases other transition processes were subsequently discussed. Those included changes in routines and lifestyles and reviews of funding packages, as people's likes and needs changed throughout adulthood.

6.1.2.1 Luke

Luke was twenty-five years old at the beginning of data collection in the summer of 2018. He had moved out of his family home five years previously. Additionally,, his mother and current day service made me aware of more recent changes to his support package. Thus, the initial focus on the transition widened and I also focused on subsequent changes to Luke's program. Luke's case contains two, somewhat contradictory sides. In some ways his case was one of the most positive ones. Luke was involved in a variety of community groups and activities, making music, art and visiting a recently designed course at the local college. At the same time his mother expressed great concerns about his future and there was a strong sense that he could suddenly find himself in a much more restricted and isolated environment.

6.1.2.1.1 Case description and timeline

The following timeline will give an overview of Luke's case and his transitions in adult services.

Figure 20: Transition journey Luke

July 2010	• Luke leaves school and starts at Day Service A. Wish for supported accommodation in the near future mentioned	Luke: is a physically very able and active young man. He enjoys hillwalking, art, music and watching clips on his iPad. He responds to simple written and verbal communication, visual timetables and social stories. Routine is important for him as Luke struggles with change and unpredictability. Luke moved into supported accommodation around five years ago. After school Luke started to go to a local day service (Service A) that focuses on further education five days a week. Two years later he moved into his own flat and the move was supported by Service A. In his flat he is supported by a different service (Service B) by a team of three to four people at night, mornings, evenings, weekends and during holidays. He continues to go to Service A Monday to Friday during the day. Some days he goes to a local music organisation that works with people with additional support needs and he has art classes. His life is described as busy and meaningful. I initially meet with Luke's mother to talk about his transition out of the family home but during my first conversation with his mother subsequent changes start to move into the foreground. The move into his flat went well but since then his mother has experienced a lengthy and stressful process of reviewing Luke's program and funding package due to changes in his support needs. There have been a number of incidents in public and this has resulted in the need to review his support plan. While there seemed to be a short time of relative stability a number of smaller changes both in relation to service provision and Luke's behaviour are mentioned by his mother.
Early 2012	• Mother approaches SW about supported accommodation • SW allocated and initial meetings	
Mid 2012	• Flat becomes available (supported by Service B) • Day Service A start to support transition	
Spring 2013	• Luke moves into his flat • Day Service A move into new building	
Late 2013	• Lukes stops joining group activities at Day Service A Five incidents over eight years. Police involved twice	
Mid 2016	• Day Service A put their price up and tensions with SW • Luke starts course at college supported by Service A	
Mid 2017	• Review meeting: Outreach program to be trialled at Service A • Incident on public bus. Police involved.	
Sept 2017	• Meeting with SW, mother and Service B • SW on sick leave and Luke's case moved to different SW office	
Jan 2018	• Meeting with new SW. Assessment resumes.	
April 2018	• Meeting at Service A. New 3-day college course mentioned • Meeting with SW at Service B. • Meeting at service A with senior SW. New funding and risk assessment discussed	
Mid 2018	• New care package send to mother and services. Mother voices concerns that details have been overlooked. New meeting planned to finalise new care package	

I was told that Luke used short sentences to communicate and was able to read and write basic sentences, but that initiation of language was difficult for him. His mother and support staff told me that he could get confused and misinterpret what was said to him and it was often difficult to gauge how much he understands. I met Luke for the first time at his day service in the presence of his key-worker Anna (pseudonym) and during our first interaction I found myself wondering how to best communicate with Luke.

OBSERVATION: *I say hi to Luke and shake my thumb in signalong. Luke whispers 'Hi'. It is faint, like he is breathing out. 'How do you say 'Hi' to people Luke?', Anna says. He reaches out his hand and I go over and we shake hands. Luke smiles. He looks at me and then looks away again. (...) Anna tells Luke that I would like to find out about the move into his flat and how he is doing at college and the day service. She tells me 'You can ask questions now'. I am slightly perplexed that she suggests that I ask him direct questions. She gives me a pen and paper and adds that I could ask verbally but that sometimes it is easier to write down questions. I don't know if I should do one or the other, or if I should do both at the same time. I am confused how to ask him such open questions. I say 'Can you tell me what you do during the day?' I also write it down on paper. Luke looks at me and then at Anna. Anna repeats to him 'What does Luke do on a Monday morning?' Ok, I think using the third person and being more concrete is better. Anna continues to prompt Luke who is looking expectantly at her. 'What does Luke do on Monday morning? Luke goes to?' She starts him off and answers the first question herself. She says 'and then?' and Luke answers, whispering the name of an organisation, where he goes to have individual music lessons. He seems tense and I feel that this is not working. I suggest that they can just continue with what they would usually do and I am happy to join them. 'Ok that's great', Anna says. She turns to Luke and says 'Now it is time to do art'. She takes a pen and says 'Now we will draw a face.' She turns to me and says 'He will copy you in the beginning. He is very good at copying.' Luke still sits in his chair. He has not gotten up once and I won't see him getting up during my time in the room. He moves his head to look at us, at the walls, at his phone, through the window. He often seems to watch us out of the corner of his eye. In between Anna reassures him by giving him a thumbs up when he must have seemed tense or she says 'You are enjoying this, I can see you are happy now' when there seems to be some indication that he is happy and content, which is difficult for me to make out.*

I start to draw a face on my piece of paper and when I draw ears Luke takes his pen and adds ears to his face. Sometimes I look at him and smile and then he smiles back. I say 'They are nice faces', he looks at me and then he looks at the wall next to him and does not respond. For a while we all sit around the table engaged in the activity. I feel a lot more comfortable now. It feels a lot easier to engage by joining in and doing

something together. (Observation vignette, study 2, case 1, Luke, June 2018)

6.1.2.1.2 Narrative conversation: Transition collage

I interviewed six people. As the transition into his flat occurred in 2013, some of the participants were not involved at the time (social worker and day service staff 2) but were involved in more recent changes. While I did not discuss Luke's specific transition into supported organisation with his social worker and the local authority officer, their general knowledge about the process was used to highlight organisational aspects.

Table 30: Introducing the actors – Luke's case

Actors	Role description
MOTHER	Luke's mother has been Luke's main carer since the death of her husband when Luke was small. She is a health professional and Luke's welfare guardian.
DAY SERVICE STAFF MEMBER 1 (DAY SERVICE 1)	She is the team leader of Luke's day service (Service A) and has been working with Luke since 2012. She was part of the team that supported Luke moving into his own flat.
DAY SERVICE STAFF MEMBER 2 (DAY SERVICE 2)	She is the project manager of Service A. She has been involved more recently in organising meetings and helping to review his support plan.
DAY SERVICE STAFF MEMBER 3 (DAY SERVICE 3)	He is the project manager of another branch of Service A and was involved in Luke's transition into his own accommodation.
ADULT SOCIAL WORKER (SW)	She got involved around a year ago to review Luke's support plan. She has been a social worker for many years

	and is most experienced working in the context of care for the elderly and with people with substance misuse.
LOCAL AUTHORITY OFFICER (LA OFFICER)	In her role she oversees the commissioning and strategic planning of service provision for adults with learning disabilities and/or autism in Luke's local authority.

Transition from school to adult services

Luke left school in the summer of 2010. His mother remembered the transition positively. She visited a number of different day services and decided that Service A was the best option for Luke, as the service offered educational activities (numeracy, reading and writing), alongside practical ones such as craft and cooking.

MOTHER: *I think what it comes down to is if you believe in lifelong learning or not. I really believe in lifelong learning. I think Luke has potential to be more than he is now and I don't think most of the day services have that belief.*

Luke's mother remembered that she was first asked about her long term wishes for Luke during the transition from school.

MOTHER: *I felt that I wanted Luke to move, to have his own life before something happened to me. And also because I thought it was more likely to be successful if we did it when he was young because he is potentially more flexible.*

After leaving school Luke continued to live at home and he attended Service A five days a week. In his second year at the service in 2012, his mother decided to approach social work again about finding supported accommodation.

Transition into flat – the organisational process

Luke's mother knew a family whose son had moved into a flat, which was supported by Service B. Her friend was happy with the service and recommended Luke's mother to enquire with social work if they might have a place for Luke.

MOTHER: *I then got back in touch with social work and said I am interested in progressing this and then they got in touch with me and then it just all happened. Looking back, I was so incredibly lucky because I*

know other people have not had this experience but that was my experience.

It seemed that the transition into supported accommodation required three steps: (1) finding an appropriate physical space, (2) finding an appropriate service provider and (3) getting the funding package agreed by social work. Most flats and houses in his local authority belonged to the council or housing associations, and the majority of support was provided by third sector organisations. In Luke's case the flat that came up was owned by the council but had been supported by Service B in the past. While the process involved social work from the beginning, it seemed that his mother's connection to the service helped the process to move along quickly.

DAY SERVICE 3: *Luke was not an urgent case per se, so he was not high priority, but then because of the nature of [his mother], she did a little bit more looking around.*

MOTHER: *I had said to the social worker I wonder if [Service B] is a possibility.*

SW: *It is a small world and people talk to each other and they might be speaking to other parents and say they might be saying to each other 'oh that works well for us' and then they might have ideas of their own.*

The flat was located in an area that Luke knew well.

MOTHER: *At the time I was working about three hundred yards away and it was beside [a big green space] so Luke is physically absolutely fine and he likes walking and it was an area he knew.*

Luke's mother started to get the flat ready. After she had started furnishing the flat, the housing department of the local authority got in touch and questioned why Luke was given the flat. The tenant who had lived in the flat beforehand had had a physical disability and housing argued that the flat should have been given to someone with a physical not an intellectual disability. This was a stressful time for his mother but after some conversations housing and social work decided that Luke could move in after all.

MOTHER: *Then the housing association said that he is not physically disabled and you can't have it and I am sort of like, I just spent all this money and nobody asked me and nobody asked [Service B] and they just assumed he was physically disabled. I did not know that it mattered at the time, so they agreed but the tenancy is actually insecure because of that.*

Supporting Luke to move into his flat - the practical process

The practical process was led by Service A. Staff from the service and Luke's mother spoke about the practical move positively, calling it an example of how to do it.

Service A supported Luke to visit his flat regularly, they had regular meetings with Service B and social work and both Luke's mother and Service A were involved in the selection of his staff team. After around six months of preparation Luke moved into his flat in the spring of 2013.

MOTHER: *He had all his toys and his videos and DVDs are his comfort thing. (...) So everything was familiar and it went absolutely perfect.*

DAY SERVICE 3: *He would start off with one night and then coming home, then it was two nights and then it was a weekend and then to be perfectly honest we would normally have extended that but Luke settled into it really well and so it was just let's move him in while it was going so well.*

Keeping both day and living service

After Luke moved he continued to attend 'Service A' during the week. A number of people reflected that this was not always the case for young people who make the move into supported accommodation.

DAY SERVICE 3: *[Service B] could not provide the kind of environment that we have and the facilities we have, and the lesson plans we had and the knowledge of Luke. (...) He was one of the fortunate ones because that does not happen very often now. It is a horrible thing to say but at the end it is about money and it should not be and hopefully that will change.*

LA OFFICER: *That has been the direction of travel for a wee bit of time now. The council has downsized its own day service provision and if somebody is moving into residential accommodation, it is the expectation that the new provider will do the twenty-four seven support and I know that some families have found that quite difficult.*

A step into adulthood

A number of people described how they felt that the move into his own flat signified a further step into adulthood for Luke and reflected on the importance to support Luke's independence instead of doing things for him.

MOTHER: *For meals he has to chop things up and help. Sometimes if he is in a bad mood he won't, but he'd do hovering, he does do chopping and we made it kind of very clear that this is his flat so he must do it.*

At the same time his day service and mother also talked about how notions of choice and independence needed to be considered within the context of his ongoing need for support.

DAY SERVICE 3: *He still does have needs and he still does have to have boundaries and timetables to make him function as well (...) with one of our students who went to an organisation (...) for example he refused to go and shower and I was saying 'You are letting him to refuse to have a shower. He knows he needs a shower, you can't sit there: 'It is up to you, it is your choice''. There has to be that boundary what is best for the individual and it has to be an agreed plan what you see as good for the person has to be agreed by everybody.*

Life at Service B – Time of stability?

Luke's mother described the first years after the move into his own accommodation as a time of relative stability before a number of things started to change, requiring her to get involved more closely again. Subsequent changes became the focus of interviews, contrasting the positive transition experience with anxieties about Luke's future.

MOTHER: *I think what my experience has been, it is, you might have a period, a short period of stability for a while but basically the life of having a disabled offspring is that there is constantly something else coming up. It is not finished. I suppose it is like that with any child, you think you are getting them through their exams, you have done your job (...) but constantly you seem to need to be part of some other thing. And certainly with Luke it feels like that.*

Changes related to changes within services and organisational practices, as well as changes in Luke's behaviour. The following discussion of subsequent changes will not be linear as some processes overlapped (see timeline).

Subsequent changes

Between 2013 and 2018 several events and incidents took place, which had an impact on Luke's life. The first change happened in 2013, when Service A moved their service to a new building. The move seemed to be connected to a change in Luke's engagement with the service, requiring the service to rethink his program. The new building had a big common area and there were fewer smaller rooms. After the move Luke started to spend most of his time in one of the small rooms and refused to join activities in the common area.

DAY SERVICE 3: *I think also because [the new building] is big and tall and very high so the noise does reverberate around it very badly and especially one or two students who can kick off, it can be very noisy and that is very scary for him because it is the unpredictability of it.*

In response the service decided to change his program. In 2016 Luke started a course at the local college for people with additional support needs. Furthermore, the service decided that Luke would benefit from more outreach activities.

MOTHER: *Although he is based at [Service A] he does not spend an awful lot of time in the building. So, he goes to college some days and other days he goes to various community groups. He copes very well with mainstream adults, that is actually his preference.*

When I visited the service a second time in June 2018, Luke had started to join a small group in the morning to share what he had been doing over the weekend. It took place in 'Luke's room' and staff members told me that they were slowly encouraging Luke to become more tolerant again of being with others.

OBSERVATION: *After the news circle the other young people and staff leave the room. One young woman is finding it difficult. She is refusing to leave, her voice is getting louder while she says 'No, no' repeatedly. Luke gets agitated. He starts looking at her over his shoulder. 'It is fine Luke', a member of staff says. 'It is all fine'. He moves his chair closer to the wall in front of his desk and continues to observe the young woman. One staff member offers her to look at pictures on her phone and so she gets up and leaves the room. (Observation vignette, study 2, case 1, Luke, June 2018)*

Then, in 2016, Service A increased their fees, which resulted in the need to review Luke's funding package. Luke's mother had paid for the service using money available to Luke through self-directed support (SDS). Social work initially refused to increase Luke's package and his mother found herself caught in the middle.

MOTHER: *[Service A] put their price up and the council would not cover it because Luke was on the maximum so we had months of us paying it ourselves or Luke paying it himself and I was worried about the whole thing because I have no control over it and there comes a point where it is not sustainable and I wanted it to be sustainable. Again just in case something happens to me, who is gonna sort this out?*

A meeting was called with Service A, parents and social work in the autumn of 2016, but no agreement was reached and Luke's mother paid the increase herself for the time being.

MOTHER: *This meeting was called in September, nothing else happened and it just went on from there into 2017 and eventually they actually did*

pay me back the money but not until October 2017. So that was like again a year. It is really challenging to deal with this because it is kind of constantly in the back of your mind.

After her experience Luke's mother decided to change her SDS payments so that Service A was paid directly by social work.

MOTHER: *I can understand how it works if you are mentally ok and physically disabled then you can have choice but if you are learning disabled and you have one service there is no benefit to a direct payment. All it means that the person who is dealing with the finances has hassle.*

Finally, there were two serious incidents that occurred in 2016 and 2017. Luke became agitated in a shop and in a bus due to the presence of small children and became aggressive towards them. His mother remembers five incidents over eight years where Luke did not cope with the unpredictability of certain situations, especially loud noises. The two serious incidents were a big concern for everyone I spoke to. The police was involved in both incidents and Luke was placed on the vulnerable adults list.

MOTHER: *I mean he had prior to the one on the bus, we had sort of taken it seriously. We twice had the learning disability team come in. So we had tried to deal with it but the one after the one on the bus that was when I just thought 'Oh my god. Oh no he is going to end up getting locked up. We just really, really got to try and deal with this.'*

Luke's mother was very concerned that another incident might result in Luke being admitted to the psychiatric hospital and she and Service A and B tried to make sure that any further risks could be minimised. At the same time his mother did not want to limit his access to his classes and activities and isolate him. To reduce the risk of further incidents it was decided that Luke should stop using public transport and the need for two carers to support Luke when out in public was discussed.

MOTHER: *Because obviously I know that I cannot allow Luke to go and hit a baby obviously but making him a prisoner in his own house is not a solution. We have to find other ways.*

Service A started to use taxis but decided to continue to support him on a one-to-one-basis with staff who knew him well. Service B started to support him on a two-to-one-basis when out in public. This resulted in an increase of support provided to Luke.

DAY SERVICE 1: *[Service B] every time he is out, there is two staff with him. And that is again they have not got the funding through from social work. So they are covering that at the moment but when he went to a theatre I think [name of staff member] was saying the other week they went to the theatre and he was so much more relaxed because he had a member of staff at each side with him. And they would be more relaxed because our students pick up on people's anxieties.*

During this time, Luke's mother got a big sum of money backdated from Luke's benefits, which was used to pay for his taxis. While the money helped to cover the initial costs, Luke's mother asked social work to get involved to review his funding package.

Getting social work involved

A social worker was allocated and during a meeting with Luke's mother and the manager of Service B some immediate help to cover the costs of the taxis was given but afterwards Luke's mother did not hear back.

MOTHER: *Eventually after several weeks we realised that she was on long term sick. There was no bounce back to her email, nobody had told us, nobody had taken up our caseload. (...) I got in touch and I spoke to somebody at social work who was her boss but he had also been off. He didn't know anything about it and (...) he said 'oh Luke has been moved to a different social work office'. (...) We had not been informed about that. Phoned the new social work office 'Oh he has not been allocated yet'.*

At the end of the year 2017 a new social worker was allocated who needed to familiarise herself with the case.

SW: *I have only met Luke perhaps twice, three times maybe, and before meeting him I was not terribly familiar with people with his or I was not professionally familiar with people with his type of disability. And so I have approached it in that I have asked a lot of questions and I have spoken to his mother and looked at all his notes and kind of done what I could to come to some kind of understanding of where he was at.*

When I got involved in the summer of 2018 the process of reviewing his care package had been ongoing for nearly a year.

SW: *The process has been difficult particularly for me cause I don't know all these processes and I don't have a history of for example [Service A]. Different services work in different ways, have different charges and Luke's, the way Luke was supported was actually quite complicated (...). He has benefits, he lives independently in a flat with 24-hour cover, he*

has a motorbility car, he has the need to have somebody with him whenever he is travelling.

The social worker needed to assess the risks and to consider what support would be appropriate and where to draw the line, which she experienced as difficult.

SW: *It is the department's job not to spend too much money while at the same time meeting our legal obligations and sometimes there is a line that has to be drawn. Is it reasonable for Luke to pay for certain things for himself? I think he has always paid [his music lessons] himself, but taxis to and from our department has restrictions of what they want to offer and I mean I found it very difficult. It was a bit like trying to grab jelly.*

Additionally, his social worker found it difficult to get an overview of how much Luke's support at Service B was costing. The service had recently experienced a change in management and it seemed to take time to get an overview of how the service was supporting him and how much they were charging.

Finalising the new support package

In July 2018 a meeting was called to try and finalise a new support package. Luke's mother felt that the new package did not take into account all details, such as holiday periods, and another meeting between the social worker, her manager and Luke's mother was scheduled.

MOTHER: *When he goes to college he is just going to have one-to-one, but if he is on holidays from college he would need two-to-one in the afternoons to go out and do something, otherwise he will be trapped in his house.*

The social worker and Service A believed that the new support package would result in a decrease of costs.

SW: *It is a more rational means of organising his week. He is not making so many journeys.*

Once the support plan and package were finalised, the social worker would stop her involvement and the case would be closed.

Changes to the guardianship legislation

Luke's mother and her sister were registered as Luke's welfare guardians, but his mother was hoping to add younger people from her extended family or close friends to the guardianship agreement. However, she was aware of recent

changes to the guardianship legislation. While she had received indefinite guardianship in the past, guardianship was now only granted for a number of years. She was worried that adding new people as substitute guardians could result in her losing her indefinite guardianship.

MOTHER: *The only thing that could possibly go wrong is if my sister and I got killed in the same car crash but as soon as one of us dies or becomes seriously ill I am going to have to do it but we are both well at the moment. And I am hoping when it comes to the time there is somebody else who will take this on.*

6.1.2.1.3 Concluding remarks

While there were many positives about Luke's life and his involvement in the local community, the family's dependence on funding and services created a feeling of uncertainty for Luke's mother. While Luke was a young man engaged in many activities, worries that this could suddenly change loomed in the background. The strain of dealing with bureaucratic processes was clearly visible in the narrative of Luke's mother. She was unable to feel that she could be confident about Luke's future due to an experience of continuous changes in legislations and practices. Both Luke's college course and his involvement with Service A were going to end in the near future, because the service had been set up as a transitions project for young adults and his mother worried about losing their involvement and expertise.

MOTHER: *I very much like [Service A] to still be involved because they have an expertise that [Service B] does not have. (...) [Service B] don't have training (...) and that is not necessary for taking him to the cinema or taking him out for a walk, but it is helpful for things like goal setting or for dealing with issues that come up. And challenges come up again and again so just things like him not wanting to brush his teeth or not wanting to use deodorant or maybe refusing to go out.*

Although the support offered to Luke by both his services was described as good, there was an awareness that organisations might lose funding, that they might restructure and that there was often high staff turnover.

SW: *I mean if he could stay in his flat that he has now forever that would be grant but you don't know that. (...) I mean he will always have to have 24-hour care and it will always be expensive. And we don't know how services will be provided in the future. We don't know.*

MOTHER: *But it doesn't feel like this will ever end this transition kind of in a way cause things change and at the moment he has got a good team*

but one of them in particular is the one who is the most proactive and she is not going to stay forever. I am just waiting for her to say I am moving on and then we will be back to 'oh god' you know.

6.1.2.2 Lisa

Of all cases, Lisa had the most complex healthcare needs and questions about how to communicate with her or understand her were the most prominent across the six cases. When I got involved Lisa was living at home. Her family had contacted social work to plan for her transition out of the family home a number of years ago but felt that the process was stuck.

6.1.2.2.1 Case description and timeline

Lisa was twenty-eight years old at the start of the study. Lisa needed close support in all areas of life and she was classed as having profound and multiple disabilities. Her vision was limited, she had severe epilepsy and her mobility was affected. I met Lisa at her home for a short time during my first interview with her mother and again at one of her day services, where I spent the morning with her and her support worker. I quickly noticed that due to her limited vision it was important to pay attention to her movements and her way of perceiving her environment.

OBSERVATION: *Lisa and a member of staff (Mia) are sitting at a table towards the back of the café, which is located on the ground floor of her day service. The café is half filled with other service users and members of staff. I say Hi to Mia and ask if it is ok to join them till after lunch. Mia says it is no problem. I sit down opposite Lisa and lean towards her. I say 'Hi Lisa, nice to see you again. I hope it is ok to join you this morning'. (...) Mia asks me something and when I answer Lisa looks at me, she reaches out and moves her hand along the table towards me. She gets up and swaps chairs so she sits opposite me now. Before she sits down, she leans forward across the table and looks at me and then leans back and sits down. She smiles. I smile as well and say 'Hi again. Maybe you did not see me properly before. Is it better now, is this a better place?' Lisa turns away looking towards the table next to us and smiles. I realise that because of her difficulties to see, her turning to the side does not necessarily mean that she turns away from the interaction but maybe she turns towards the sound I am making. I keep talking to Lisa and she smiles, rocks back and forward in her chair and waves her hands in front of her face. (Observation vignette, study 2, case 2, Lisa, August 2018)*

Figure 21: Transition journey Lisa

Dec 2008	• Lisa leaves school and starts day services in the new year. Wish for supported accommodation in the near future mentioned	Lisa: enjoys going for walks, music, she likes her trampoline in the summer and going in the car when it is moving. Lisa is a social young woman and her family tell me that she likes to spend time in the common areas of both her day services where it is busy and she can be in the company of others. She likes to sit among people and move from chair to chair. Lisa mainly communicates through her behaviour, expression and gestures. She can use words to express how she feels but some words have their own meaning. For example, she repeats the name of a family member when she is in a good mood. After school Lisa starts to go to two different day services, one three days and one two days a week. The family have always known that the move into supported accommodation will be the next step and as her parents are getting older their wish becomes more urgent. Her family would like to avoid a crisis situation and to be able to support her and plan the move. The wish for supported accommodation is first mentioned to social work when Lisa is around twenty. Her parents communicate their wish again with more urgency in early 2017. Their social worker starts the assessment but then the process feels stuck for many months as the social worker falls ill and is off work. The family gets a new social worker towards the end of the study and the assessment is resumed.
Early 2010	• Mother mentions wish for accommodation to new SW • Family put Lisa's name on housing lists	
Early 2017	• Family approach SW and communicate wish for supported accommodation more urgently • Family meets different service providers in their locality • Multidisciplinary planning meeting agreed • Planning meeting cancelled various times	
Late 2017	• Planning meeting at parents home. Next meeting planned for April	
Early 2018	• Parents receive SW report from planning meeting	
April 2018	• Parents are informed that SW is off sick. New SW allocated	
May 2018	• LD nurse visits family and contacts SW to get ball rolling again • Senior SW contact family and informs them that new SW will contact them in August	
Aug 2018	• At the end of August mother contacts SW to ask for update	
Sept 2018	• New SW visits family to start new assessment. Family is informed about new houses being build in the local area	

The timeline includes Lisa's transition from school to adult services at the end of 2008 and the family's first contact with social work about supported accommodation. While her mother says that she continued to think about the move into supported accommodation during subsequent years, she had the understanding that social work would take initiative. However, as no meetings were called over the following years, she approached adult social work again in 2017. No decision was made, and no accommodation was identified during my involvement with the family. A number of meetings were held but the process continued to be in the early stages.

6.1.2.2.2 Narrative conversation: Transition collage

For Lisa's case I interviewed four people. As no official contact with service providers had been made, the interview with the project manager of a local supported living provider was not case specific but helped to illustrate the local service provision context. Thus, Lisa's case was dominated by the perspective and views of her mother and brother.

Table 31: Introducing the actors – Lisa's case

Actors	Role description
MOTHER	Lisa's mother is her main carer at home since her husband has developed physical health problems. She used to work within health services and is now retired.
BROTHER	He is Lisa's older brother and visits her at home about every one to two weeks. He is registered as her substitute guardian and has been involved in review meetings about her future.
FAMILY SUPPORT SERVICE	She is the team leader of a local family support service that supports family carers. She has been involved with the family during workshops and discussions within their local authority

	that cover topics such as the transition into supported accommodation.
LOCAL PROVIDER	He is the project manager of one of the main service providers for supported accommodation in Lisa's local authority. Lisa's mother had some initial contact with the provider and it is her preferred choice alongside two other local providers.

Transition from school

Lisa left school in December 2008, six months earlier than anticipated, as places at two local day services (Service A and B) became available.

MOTHER: *Well we thought she might stay till she was 19, but a place came up at [Service A], and [Service B] were able to take her as well. So that was the right time for her to leave, cause the places were available and if you don't take them up, they might disappear.*

Her parents decided that Service A and B were most suitable as they had expertise in supporting people with complex needs and visual impairments. Furthermore, she felt that the two services offered Lisa access to different environments and activities.

MOTHER: *I think she quite enjoys sort of having the two services because they are a bit different. People are a bit different and she gets slightly different opportunities at each. I think she would be a bit bored if she went to the same one.*

Her mother felt that the process went well overall, but she recalled a short period of tension between social work and Service A about the funding.

MOTHER: *It felt as though it was a bit of a delay because [Service A] wanted an agreement of funding and social work said we won't agree to funding until a place is there sort of, however it got sorted.*

She felt that the process went well because she started to plan for it early, a year in advance, and both services were able to get to know Lisa before she moved.

Life at both day services and at home

Lisa had been visiting both day services since January 2009 for five days a week from 9am to 4pm. Her mother felt that Lisa enjoyed both services.

MOTHER: *When they [transport] arrive in the morning she is 'oh hello' and goes off happily with them.*

Her day services were building-based and offered activities such as trampolining, music, arts and outings in the local area. At home her mother and Lisa went for walks and she took her to a dancing session once a week. At weekends and holidays the family received further support at home from personal assistants. Lisa regularly met with a small group of other young people with profound ID. The families knew each other well.

MOTHER: *They might go bowling, go and have a meal out that sort of thing.*

Overall, Lisa's life at home was described positively, but both her mother and brother described how it could be difficult to plan and do activities with Lisa.

MOTHER: *She probably doesn't like terribly crowded, terribly busy places and some places where it is very, well she is ok with loud noise but sometimes if it, sort of very echoey type noise.*

BROTHER: *Sometimes she will just wander off without, when she gets bored or if she does not want to interact with people, the same person all the time, and she will wander off. Sit on the floor, do her own wee thing, her own wee head space. I guess this has become a little bit of an issue if like her family or other people take her to a restaurant or a café with them because she will only sit patiently at the table for a short time.*

Approaching SW about supported accommodation

Around the time of Lisa's move from school to adult services, her mother made social work aware of the family's wish for supported accommodation. Lisa had been allocated a new adult social worker and her parents talked to him about their concerns.

MOTHER: *It was probably around 2010/11. It was certainly after she left school so round about that time [X] became Lisa's social worker. (...) It was just making them aware. I was also making them aware that if I was not capable of looking after Lisa for whatever reason she would need to be housed urgently, because my husband has a variety of medical conditions that he really wouldn't be able to physically cope with looking after Lisa.*

The family was advised to put Lisa's name on different housing lists. They did but described how the process had started to change and that housing for Lisa could now only be offered through social work. I got the sense that there was uncertainty about the process and the roles and responsibilities of families, providers, social work and housing associations.

MOTHER: *I think the social worker did say you ought (...) to sign up for a housing association. So we actually did that about ten years ago and someone from housing said do you realise if you are offered housing and you refuse two than you go to the bottom of the list. (...) When she was on the list it was being postponed, which did sort of accumulate a point or two each year. (...) But the system in [the local authority] for housing has changed (...). You make a bid for it sort of thing whereas the other housing associations it is still I think points based. [One housing association] is only through social work and they all say well you also need support through social work because she is not homeless etcetera.*

FAMILY SUPPORT SERVICE: *I have to say at this moment is someone came to me with an enquiry afresh I would have to go and do some research because what I always thought would happen does not seem to be happening. And sometimes it does vary from local authority to local authority and in some cases, people have been told to join the housing list but then I don't know where it leaves them with regard to the support they are going to get.*

Once the family had made social work aware, they thought that social work would start to look for possibilities. However, as nothing happened, she started to look for options herself and tried to move the process forward.

MOTHER: *Well when we mentioned it a few years ago we were told 'oh social work commissions somebody to look for accommodation and a package' and so on but I think that has changed.*

FAMILY SUPPORT SERVICE: *Although we would never have thought of social work as having a lot of money for social services, when we look back we see that they had a considerable amount more than they have now. In those days what the senior social workers had said to us was, if you are thinking about supported living for your relative the best thing to do is to plan in advance. Speak to your social worker now. Give them three, four years notice before it is an emergency situation. (...) By the time Lisa's mother had raised it with me, I knew that that planning was just not taking place in any local authority now and in fact if you approach a local authority they are more likely to say is this a crisis situation because if it is not, we can't deal with it.*

The wish for supported accommodation becomes more urgent

Lisa's family felt the need for accommodation was becoming more urgent. As both parents were getting older, they wanted to prevent a crisis situation. Thus, the family contacted social work again in the beginning of 2017.

BROTHER: *It's been talked about for several years, but I guess it has really been first talked about seriously in getting social workers together, carers together (...) sort of probably just over a year ago. (...) My dad is seventy plus my mum is sixty plus and my dad has quite a lot of health problems. (...) Hopefully fingers crossed it does not happen for another decade but potential is there that something could go wrong.*

FAMILY SUPPORT SERVICE: *That is a very common concern for our aging families and even those who are not aging are still very aware that (...) at some point in the future their daughter or son is likely to outlive them.*

Lisa's mother started to contact different providers herself to find out more about possible options. Ideally, the family wanted Lisa to share accommodation with two of the young people she met regularly, and for the care to be overseen by a provider instead of employing staff themselves.

MOTHER: *We had also approached one of the families, the girl which she goes out with sometimes on a Saturday, and we approached another family too and the possibility of the three girls sharing accommodation, one for the company and two to make overnight care simpler, and we thought there would be more people going in to just make sure that everything is ok. (...) We went to see (three local providers) I think. It was really just to sort of begin to get a feeling for what is out there. But we can't go ahead with that until we know which package we are going to get. (...) The other option is to have personal assistants but you are then responsible for making sure there is enough, particularly with holidays and illness and all that sort of thing, and that gets quite complicated.*

Once Lisa moves into supported accommodation her family would like her to continue to access her day services.

BROTHER: *It would give her an anchor to fall back on, where part of her day would still be the same as it was before.*

MOTHER: *People will say as she goes into the place 'Hello Lisa, how are you?' They give her a nice warm greeting and that is I think quite important that she feels 'Oh I am in a place where people know me. I know where to go.' It is not if you were doing lots of new things in the community she wouldn't know where she was.*

Lisa's mother was aware that local authorities did not always agree to fund both, day services and a supported living service. She felt that there was little consistency as she knew families whose children recently had been able to have both and others who did not.

FAMILY SUPPORT SERVICE: *The argument is well if we are paying for staff to run a house then we are not going to pay for 'Jimmy' to also be out five days a week. My argument would be, apart from everything else, the staff who got jobs to support people at home might not have the same level of skills required to do all the active engagement that the day centres did. Music therapy, art therapy, physio all sort of things. (...) Also people are losing out on a whole community involvement and all their friends and family. so that is a real challenge for people.*

Lisa's mother was concerned that there was a lack of suitable activities for Lisa in the local area and that it would be difficult for staff to find meaningful activities for her outside her day services.

MOTHER: *They need to look at what activities are available, what she likes to do and also organise social activities (...) where it is a social group where she is accepted as she is. Because at Service A and B and respite care she is just accepted as she is. (...) They can't just sit in the house and do nothing with her. She has to go out and do things.*

An initial planning meeting takes place

While Lisa's mother gathered information from providers and housing associations, she was unable to move the process forward without the support from social work. A planning meeting took place in November 2017 to start the assessment process. The meeting was held at the family home and included Lisa's parents, brother, social worker, staff from both day services, her respite service and her personal assistants.

MOTHER: *For various reasons the planning meeting got cancelled at various times, but we eventually had the planning meeting at the end of November and ourselves and Lisa happened to be present and various services there. (...) It was really an assessment of sort of who Lisa is, what she is like as a person, what she likes to do. (...) Really didn't talk about much about her, what level of care she would need. (...) We were going to have another meeting with social work at the end of April to discuss overnight care and the kind of care package that we would be thinking about. However, unfortunately social worker was taken ill.*

I spoke to Lisa's mother and brother in July 2018 and at that time the family had not heard back from social work nor had a new social worker been allocated.

BROTHER: *Unfortunately the whole process is moving quite slow (...) I worry that it might be five years down the line and if you make it five years rather than two years the likelihood of something happening to one or both of my parents increases dramatically. (...) I worry for my parents. I worry that Lisa won't get the best opportunity that she maybe could, because the council are dragging their feet and maybe my parents are not aware of the opportunities they might be entitled to (...) and Lisa gets stuck in a flat that is not suited to her (...) and she ends up having to move out in the space of a 48 hour notice or 72 hour notice.*

The family was particularly anxious to discuss Lisa's need for overnight care, as they had heard that their local authority had started to replace overnight staff with technological solutions, such as sensors and monitors.

MOTHER: *We have to know that Lisa gets overnight care because for her epilepsy, especially apart from her learning disability. If the package doesn't quite add up to the full 24-hour care we were thinking, well if there are two or three of them together, then that would give them a sufficient package to provide overnight care but that is still to be sorted out.*

PROVIDER: *The sleep over is costing something like thirty odd thirty-three, thirty-four thousand pounds a year. Now with the [Scottish Living Wage] going up (...) it is going to cost (the local authority) 2.4 million pounds for sleepovers now that the rate is gone up so they are saying to us how can you do this more efficiently.*

BROTHER: *I think she needs 24-hour care because Lisa might not be willing to stay in a bed, she might get out of it and then if she had a fit on the floor or somewhere where there was not a sensor then that might cause problems.*

Lack of housing

While the process seemed to stagnate because the social worker was off sick, participants also described that lack of housing was a main issue. Lisa's parents had started to consider buying a property for Lisa themselves. However, again, there seemed to be confusion about the process and who would be responsible for the property should Lisa's parents pass away.

MOTHER: *There is very little suitable accommodation in [the local authority] anyway and it is all sort of booked up (...). So in fact the last time the social worker was out he said have you thought about private renting. So I assume quite a few people are now going into private rent, which to be honest I am not too keen about, but I know some people have bought so that would be the other possible option of buying somewhere.*

BROTHER: *With the housing shortage being as it is just now the council seemed to suggest that a four-bedroom flat, which is what the three of*

them would need plus for a carer would be very difficult to find just because they are in demand by families. (...) I don't think [social work] really appreciated or provided support to my parents, which is the main thing, but also there has always been a sort of great negativity towards some of the ideas of my parents like sharing the house with a second or third person.

Getting a new social worker: Progress resumes

During my last meeting with Lisa's mother in the middle of September 2018 there had been some new developments. Shortly before my first visit in July, Lisa's learning disability nurse had come to see the family and had taken initiative to follow up Lisa's case with social work.

MOTHER: *She contacted the senior social worker who phoned to say they are short of staff because it is summer holidays. She expects to have someone with us some time in August.*

Lisa's mother contacted social work again at the end of August 2018 and a new social worker got in touch with the family at the beginning of September.

MOTHER: *I actually phoned at the end of August to say what was happening. Apparently, there is another person off ill and they have all been very busy but she told me that [X] would be our social worker and that she would be in touch within a week or two, which she was. She phoned last Monday and we saw her this Monday. So I get the feeling that perhaps things are beginning to move a bit.*

During the first meeting that Monday the social worker told the family that there were plans for new houses to be built in the local area.

MOTHER: *The social worker this morning said that Lisa would be in the priority list and she has to fill in some special needs assessment form, I am not sure what it is but anyway, she said that she would do that. So there might be something happening. I don't know what yet (laughs).*

The housing development was still in the early stages, but Lisa's mother was hopeful that the process was now starting to move forward.

MOTHER: *It is at the stage of, you know, they are clearing the land (laughs). So there is not going to be something in the next few weeks, but maybe within the next year. But she didn't say anything about time scale. (...) It feels as though if there is more housing going to become available then it sounds like we have a chance of getting a house for Lisa somewhere and I am not too worried where, as long as it is in [the local authority].*

During the meeting the social worker indicated that Lisa would be eligible for overnight care and her mother also felt that the social worker seemed open to the idea of shared accommodation.

MOTHER: *It sounds as though that she thought Lisa would get 24-hour care, because she has epilepsy (...). I don't know if she can say that with authority, but I mean she thought that would not be a problem. (...) She is aware that we are keen to share. (...) She did say that [the local authority] are now coming round to the thought of more people sharing. I think for a variety of reasons. Some people who apparently are living by themselves are wanting to now share, some people are the other way around but also in terms of care it makes a lot more sense. She did say they are rethinking it, so maybe they will. (...) I feel that there is a bit of hope on the horizon.*

6.1.2.2.3 Concluding remarks

Lisa's transition includes different stages and turns that can be part of transition processes, frustrations of not hearing back and being left in the unknown, and then becoming more hopeful as professionals get back in touch and new information is shared. Additionally, Lisa's case involved interesting reflections on inclusion and community living. During interviews all participants spoke about their views on existing service provision and service models that they felt were needed and links were made to the past of institutionalised care. Lisa's brother and mother described Lisa's day services as inclusive in contrast to mainstream activities, which they felt were often unsuitable or inaccessible to Lisa. Both talked about how shared group living could offer Lisa a sense of community. The manager of the local service provider on the other hand connected shared living with institutionalised care, arguing that it offered less possibilities for personalised support. However, he later on described how single tenancies could result in people being more isolated.

PROVIDER: *We have three, four bedded flats that all people share. They share a living area, a kitchen and they all have separate bedrooms. It is not the most modern model if you like. (...). I think at the time it was a type of model where we could provide lots of support for people that is more efficient, a kind of shared support and it was not ideal. I think and with the years we have moved on we are a lot more personalised and we are a lot more focused on individual supports. (...) The move from people all living in houses, all shared accommodation, to then individual tenancies, I think it is a great idea but what tends to happen sometimes and it depends on your staff team you can become quite isolated and your staff team become everything for you. Your friendship they provide everything for you.*

While everyone agreed that it had been important to move away from the time of institutions, participants discussed that a move away from shared support towards single tenancies did not automatically result in inclusion and better quality of care. It seemed as if participants struggled to define what 'inclusion' and 'institutions' meant in the present context of reduced resources and funding.

6.1.2.3 Ben

Ben's case differed from the others, as he was almost forty and had moved into supported accommodation fifteen years ago. Thus, his case offered an interesting exploration of different bigger and smaller changes throughout his more than twenty years in adult services.

6.1.2.3.1 Case description and timeline

Ben was thirty-nine years old when I started my study in 2018. He lived in a small house with two other women with ID. The three had been supported by the same local service provider for fifteen years. Ben had complex epilepsy and severe ID. More recently people felt that Ben seemed more tired and less active. His parents and staff were not sure if this was due to a change in his epilepsy or if he was getting older and therefore needed more rest at times. I visited Ben at his house and spent one afternoon with him and one of the members of his support team, who I will call Eva (pseudonym)

OBSERVATION: *I arrive by train and then walk to Ben's house. I can see him through the window sitting in the living room with his support worker (Eva). She waves at me through the window and comes to the door. Eva knows about me and my visit. We walk together into the common area, with a sofa area and TV and in the back there is a dining table. One door leads to the right to Ben's room, two more rooms are upstairs. There is a backdoor that leads to a small garden. Ben sits on the couch and he gives me a broad smile when I enter. Eva goes to sit on the couch opposite. I say Hi to Ben, introduce myself and go to sit next to him. He moves closer to me and holds out his hand. I reach out to shake his hand. He takes my hand and squeezes it. Ben leans back on the couch and closes his eyes while smiling. 'He is tired today', Eva tells me. (...)*

Later on we drive to the waterfront for a walk. Eva pushes a wheelchair and Ben walks next to her as we walk slowly towards the waterfront. Once we are around the corner he reaches out to hold her hand. She asks him if he would like to push the wheelchair. She says it helps him to keep balance while walking. She moves the handles towards him, but he does not take them and continues to walk next to her holding her hand. We walk slowly. Ben taps on Eva's arm and says 'car'. She laughs 'No lazy bones. It is time to walk and move a bit.' Ben stops and taps her arm again. She looks at him and he says 'car'. 'Now we walk', she says. We walk for five more minutes. Then Ben stops and taps her arm. 'What is it?' Eva asks turning towards him. He points at the chair. 'Do you want to sit in the chair?' she asks. He smiles and moves towards the chair. We continue to walk along the waterfront and back with Ben sitting in the wheelchair. (observation vignette, study two, case 3, Ben, August 2018)

Ben's timeline spans the longest time period of all cases. Ben's parents asked to use his age in the timeline to mark the different changes in his life instead of specific dates. They felt it helped to get a better sense of the timeline. While the interview schedule and focus of the interviews was initially on Ben's move into supported accommodation in 2003, when Ben was 25, interviews with parents included reflections that spanned from Ben's early years, to the move to a residential secondary school, the transition to a residential college and moving back home shortly before his 22nd birthday, before his move into supported accommodation in 2003. Additionally, his parents and service team leader reflected on more recent changes and their views about his future. An overview is provided in the following timeline.

Figure 22: Transition journey Ben

Ben is 14	• Ben attends school in local area. Parents feel it is unsuitable • Ben moves to a residential school one hour drive away	Ben: loves music and to be outside in nature. He is a communicative and interactive man who likes to engage with people. He uses a few words, signs and body language to communicate. After visiting a local primary school, Ben moves to a residential school in a different local authority and later to a residential college in an out of area placement in England. His parents started to actively look for a place for Ben to live when Ben was at the residential college. Ben is an only child and his parents wanted to allow for enough time to support him, reassure him and address any problems during the transition into supported accommodation. Ideally, his parents would have liked him to leave college and move straight into his own accommodation but there was a delay in the process. Ben came back home after college for two years before he moved into a shared house with a young woman who had gone to the same school as Ben and another woman, who the family did not know. Ben's parents had identified their preferred service provider early on. The family are very happy with his placement. He is supported by staff to access activities in the local community and his parents and the service work closely together.
Ben is 19	• Ben finishes school and moves to a residential college in England • Ben transitions to adult health services • Ben's mother visits different accommodation providers • She makes contact with Service A, as her preferred choice	
Ben is almost 22	• Ben moves back home. During the day he is supported through an outreach program by two services	
Ben is 24	• A house is identified, which will be supported by Service A • The house is for three adults. A family known to Ben had been identified beforehand. A third family is identified by SW • While the house is being built, staff is recruited. Staff visit Ben	
Ben is 25	• Ben moves into house into an upstairs room	
Ben is approx. 30	• After a number of falls down the stairs an extension is built to allow Ben to live downstairs	
Ben is 39 2018	• Ben's medication is reviewed and changed • Ben appears to be more tired • Due to changes in seizure activity a request for waking night staff is made. Service A find it difficult to fill the posts	

6.1.2.3.2 Narrative conversation: Transition collage

I conducted five interviews. The interviews with the team leader of the family support service refers to the same interview that was included in Lisa's case.

Table 32: Introducing the actors – Ben's case

Actors	Role description
MOTHER	Ben's mother used to be his main carer at home when Ben lived with them. She worked within healthcare and is now retired.
FATHER	Ben's father is now retired. He used to work within building and construction.
SERVICE A TEAM LEADER	She has supervised staff and worked with Ben for over fifteen years. She was involved in organising his transition into the service.
FAMILY SUPPORT SERVICE	She is the team leader of a local family support service that supports family carers. She has been involved with the family during workshops and discussions within their local authority that cover topics such as the transition into supported accommodation.
LOCAL AUTHORITY MANAGER	He is the manager for the adult learning disability team within the local authorities' health and social care partnership.

Early years and move to residential school

As a young child Ben started to visit the local nursery and then went on to attend a special needs school in the local area.

MOTHER: *He did attend the local nursery school when he was three. The health visitor got him in there just because he was not socialising very much and that was actually one of the best things she did for us although*

if there was ever any outings or anything I had to go along because of his epilepsy.

Because of his exceptional healthcare needs, access to therapies had always been important to support Ben's wellbeing. Fighting for access to therapies seemed to have been an ongoing topic in the life of his parents, starting during his early years. His parents felt that the local school was not able to provide the specialist support that Ben needed and they wanted him to move to a residential school (School A) with more specialist input.

MOTHER: *They did not have occupational therapy, they did not have physiotherapy and so we scouted about for somewhere else for Ben and we found [School A]. (...) Now Ben would have been about thirteen by this time and we went out to see the school and we were quite impressed by it and we decided that we would transfer him to [School A]. I mean it was a big shock for Ben I think because he never really been away from us, well from me.*

Ben lived at the school during the week and came home at weekends and his parents visited him once a week.

Move to residential college

Ben went to School A until he was nineteen. His parents wanted him to continue to learn and access education. They felt that there was, and still is, a lack of services that continue to promote education after the end of school and that there were no suitable services available in their locality. Ben moved to a residential college in England at the age of 19, with access to nursing staff, physio, horse riding and music.

MOTHER: *There is a great lack of education after children leave school. No opportunity to retain and improve what has been learned. If there had been something in the locality, that would have been wonderful. We were fortunate that the council financed Ben going to a residential college. This was, of course, before 2008 when austerity started.*

Although they were happy about his placement, his parents struggled with him being so far away from them.

FATHER: *He had some quite bad falls. We would get a call to say that he was in hospital and you are three hours away and we needed to wait to hear if it was serious or not.*

Starting to look for accommodation and becoming aware of Service A

His parents started to look for possible accommodation services when Ben was still at college.

MOTHER: *I was going and seeing places, trying to get a feel for the atmosphere, just is this a good place for Ben to be. Are the staff good? Are they properly trained?*

His mother heard about Service A, a service for people with complex medical needs. She contacted the service and after a number of visits decided that she would like them to support Ben in the future.

Coming back home

Ben left college after three years and moved back home for three years between the ages of 22 and 25. My two interviews with Ben's parents in 2018 included two different reflections on his move back home. It seemed that his parents had wanted him to move straight into supported accommodation but they had not been able to secure the right housing on time. Yet, in the first interview his mother also described that she had wanted Ben to stay home longer and that she had questioned if the move into supported accommodation had happened too early.

FATHER: *[Ben's mother] was trying to organise so that he would leave college and go into his own accommodation but it did not work out that way so there was a delay so he had to come back home. (...) There was not any housing.*

MOTHER: *Ben came back from college when he was, he was nearly 22, and went into supported accommodation when he was coming up for 25. So, I suppose in many respects, very originally in the beginning we had thought getting Ben a place somewhere when he was about 30. We kind of thought 25 is quite young.*

During his time at home two different service providers supported Ben through an outreach program.

MOTHER: *They would come and take Ben out between 10 and 3 Monday to Friday (...) Two very nice young men who came and took Ben out to different activities but he was staying with us obviously for that period of time.*

The transition into supported accommodating

During his time at college Ben's family had been in contact with social work about finding housing for Ben. New houses were being built in the local area and some of the houses were being earmarked for local authority housing. It was difficult for me to understand in how far his parents had been able to make a choice about the service provider or in how far Service A being one of the preferred service providers for the council and new business being up for tender, just naturally came together. Overall, Ben's parents described the process as positive and parent-led.

SERVICE A: *There must have been (a choice) at that time. I am surprised to be honest. I certainly would not think it would be the case in this day and age. It will come down to money but yeah there must have been a choice, which is good.*

Ben's parents described that Service A was involved early on in their communication with social work and it was agreed early on that they would support Ben. Ben's parents wanted Ben to share a house with others and two other adults with ID were identified.

MOTHER: *I had spoken to [a family that we knew]. (...) I knew [their daughter] from when she was a wee tot and so we thought it might be quite a nice mix the two of them because, I knew they did not have anything specific in common (...), but the thing was that they knew each other (...). [Service A] just got in touch with the social work department and they negotiated the payments, the housing all that sort of thing and it was at that time that they said they were building in [the local area].*

One of the houses being built was identified for Ben. Ben's parents liked the area but looking back, both his parents and the team leader of the service reflected how the design of the house was not ideal in terms of accessibility, as it had stairs.

MOTHER: *His [former class mate] is actually in a wheelchair so they installed a lift in the living room and I think back, it was pure madness really. It would have been cheaper to just have had a bungalow so that people could just be on the one level.*

The house was for three people and the council identified a third woman to move in. Before the move all three families met. While no one mentioned any issues or problems between the three housemates, Ben's parents felt like there was no choice about who Ben and his school friend would live with.

MOTHER: *I mean it has worked out ok over the years. (...) [but] nobody came back to us and said look this is what we have decided how do you feel about it? (...) I don't think the way it was done was very good that is what we are saying aren't we?*

FATHER: *Yes, you had no choice.*

SERVICE A: *It is almost I think a wee bit like student life where you are all kind of flung together but in student life after two, three years you go your separate ways and in the care situation that is not going to happen.*

Preparing Ben for the move

While the house was being built, Service A started to recruit staff and organised for staff to get to know Ben. The team leader felt that it was challenging to prepare Ben and the team while the building process was ongoing.

SERVICE A: *We did not have a base. Which is incredibly difficult. This was literally a building site.*

His parents took Ben regularly to visit the building site and neighbourhood.

MOTHER: *We watched the house been built just to kind of familiarise Ben with the area and kind of kept talking to him about 'this is where you are going to stay' cause I think it is quite important although you are never very sure just exactly what level of understanding Ben has. I think we always have to give him the benefit of the doubt.*

Life at Service A

Staff from the two services who had supported Ben at home were not involved in the transition. Looking back, the team leader felt that their input could have helped. She remembered that it was difficult in the beginning and Ben and his staff needed a couple of years to get to know each other.

SERVICE A: *I think it took (...) a good two to three years as you are starting to build up the communication and understanding him better. (...) When I reflect back because I know the man now so well and I think he is happy. I think I can see that. I didn't necessarily see the unhappy man. I saw the challenges that it was for me and my service and the team but on looking back yeah I think I can see the sort of unhappiness and huge worries by his parents understandably.*

While Service A experienced regular staff turnover, Ben's team leader had been in her role from the beginning and there were around three members from the original staff team that still worked at the house. Ben's parents visited him most Sundays and regularly went on family holidays together. At the service Ben was involved in different activities. He regularly worked on a local farm, went to a local

music group, swimming, attended a sensory group and visited a local activity centre most weeks. It was important for his parents that Ben continued to be engaged in meaningful activities and they continued to be closely involved in finding out about possible activities. His parents felt that it could be difficult to find activities in the local area that Ben could access but they also felt that meaningful activities could be small things that kept Ben involved.

FATHER: *No matter how small it is. Whether it is putting cutlery away or actually getting out and doing something.*

As Ben had been living in his house for fifteen years, I tried to get a better understanding of how the service felt they were able to involve Ben and include his voice in everyday decisions. Due to Ben's limited verbal communication his team leader highlighted the importance of attuned relationships to listen to and hear Ben. Later on in the interview his team leader gave an interesting reflection in relation to the role of friendships in his life and how organisational difficulties could at times stand in the way. It reflected how Ben depended on staff to facilitate his involvement.

SERVICE A: *He had a very good friend, who he knew through kind of the school system and they went to a club together and we managed to keep this friendship going where she would come for dinner to the house. (...) But she then went into supported accommodation as well and it started to fizzle out. Our staff would phone and they would say 'oh there is not enough staff' (...) It is completely about staff having the right attitude and making that effort to maintain friendships and relationships and if they are not willing to put in the groundwork, which is making the phone calls, cause the person can't do it themselves, then it is not going to happen. (...) Imagine your life being dictated by that. That is a real tough one.*

Subsequent changes – 'You never get bored. Things are always changing.'

(Service A team leader)

During the last fifteen years living in his house Service A needed to respond to Ben's changing needs, resulting in two main changes throughout the years. When Ben was around 30 years old a number of incidents occurred, where Ben fell down the stairs. Originally, all bedrooms were located upstairs in the house but after the falls, it was decided that an extension should be built in order to allow Ben to live on the ground floor.

MOTHER: *He had fallen down the stairs a couple of times, both times blue lighted to the hospital and one of the times he was pretty concussed*

and anyway [Service A]. negotiated with the local authority and they built on a unit for Ben.

There seemed to have been some initial discussion about Ben moving to a different house, but his parents felt that it was better for him to stay in the environment he was familiar with, instead of him moving again. Additionally, his parents remembered that the council had problems to find a suitable alternative and so agreed to fund the extension. More recently Ben's parents and the service had started to review his night support and felt that it needed to be changed from a sleeping, to a waking night attendant. The service had always had one member of staff sleeping over at the house, but Ben's parents started to be concerned that someone asleep might miss seizure activity. Additionally, because of his epilepsy Ben was described as having an irregular sleep pattern, meaning that he could be awake at night and leave his bed.

MOTHER: *We feel it is much safer for Ben because the sleep over staff are upstairs and Ben was outwith the building if you know what I mean because even if he had shouted out I sometimes wonder if people might have heard him and I kind of worried about that a wee bit.*

FATHER: *His door was alarmed but only if he got up and tried to get out. If something was happening in his room, they wouldn't know.*

While funding for waking night staff had been made available Service A was struggling to fill the posts.

SERVICE A: *That is an additional three members of staff. So, we now got a team of thirteen. We were given that funding a long time ago, but we tried and tried to recruit. We had one member of staff from the day shift wanting to do the night shifts so we would need to back fill her post. We could not fill the post. So, we had to just keep saying to the social work we are trying, we are trying.*

Problems to recruit social care staff were mentioned by all participants. In my fieldnotes I reflected how this example showed how wider issues within the social care sector directly influenced the life of Ben.

LA MANAGER: *The care sector in this point in time is struggling in terms of recruitment because people are not attracted to the job like they might have been ten years ago. (...) There is other types and roles and jobs in society that people can go and work in a shop and supermarket, which is much less challenging and you get maybe the same salary for it, the same wages for it. (...) You need to pay people for good quality care and it is not cheap.*

Overall, people felt that Ben's needs were increasing and that he might have entered old age as a new life stage. Yet, it was difficult for people to know if changes in his abilities were connected to recent changes in his medication or old age.

MOTHER: *He has changed a drug. (...) I still think it is affecting his mobility, but it is so difficult to tell whether it is that or if it is just age. (...) I mean his quality of life is still very good, but we can see a change in him yeah. He is getting older and so we need to try and accommodate that.*

SERVICE A: *He was in his twenties, now he is going to be forty and it is the same with the other people we support, their lives, their abilities, are changing, that are probably speeding up to older age quicker than ourselves due to their health needs. (...) I had a few good conversations (with his parents) about from both sides, how will we support Ben when they are gone (...) and then we have had the other conversation about end of life for Ben. I know they have said to the social work, no we want Ben to be supported by Service A to the bitter end and I said absolutely that is what we would like to do and if we needed additional training, we would do that. However, it might become out of our hands when he needs palliative care. We just don't know the future.*

Views on past and present service provision

Throughout my conversation with participants they talked about different service models and shared their thoughts on what makes a service a good service. Shared accommodation seemed to be linked to 'older' models of care, while all participants also voiced concerns about single tenancies for adults with high support needs. Some felt that smaller houses with shared support might become more relevant again.

SERVICE A: *When I was doing my training in the 1990s single tenancy houses just sound like that is it, you made it. If you got Gogarburn and Lennox Castle as institutions here, and then you have a single tenancy, 'oh my god it does not get much better than that'. Now twenty-one years I have been working for this company and I can see massive problems and flaws in single tenancies. Firstly, incredibly expensive (...) but there is so much more to it than that. Single tenancy there is isolation by the service user, the member of staff can feel isolated. One to one for 24-hour support there is opportunities for abuse on many levels: financial, physical. (...) If there is three staff on today you are watching other people's work practice whether you are meaning to or not plus I am on top of that. (...) Single tenancies you don't.*

LA MANAGER: *What we are looking and we have commissioned a number in the last few years, the most successful model seems to be places where people have enough space in their life to be able to be*

alone when they want to, but also have company when they choose to as well. (...) So we have commissioned a number of services with reasonable size houses where people have a kind of small flat type arrangement and the other person is the same and there is a middle ground because there might be a dining room, lounge facility where they can come together when they want to do that.

MOTHER: *We didn't want [a single tenancy]. I think for two reasons: One it would have been very isolating for Ben, he needs the company of other people (...) but a house of ten, he would have been overwhelmed. So, we just thought a small group would suit him better plus I think it would have been very hard on staff. To support Ben, I think it would have been 12-hour shifts, one at day and one at night. I think to be perfectly honest the turnover of staff would have been very high, especially at times when he is going through seizure activity and seizure changes.*

6.1.2.3.3 Concluding remarks

Although Ben had moved out of his parent's home fifteen years ago, I was struck by his parents continuing involvement in his life, particularly in finding suitable activities for Ben, researching about new equipment and finding ways to make Ben's life more comfortable. In Ben's timeline, which spans over 20 years, the centrality of the family network stands out. Thinking about a future where his parents, who had always been the constant in his life, would not be able to be as closely involved, I felt that this must be of great concern for his parents. Instead I found his parents were probably the most positive about the future of all parents I had interviewed. His parents and Service A had talked about the future and that the service would need to support Ben through the process of aging as well as possibly supporting Ben through the loss of his parents. Ben's parents had taken on welfare guardianship about nine years ago. They wanted to consider guardianship more closely in the near future again, hoping to find younger relatives or friends to get involved, but they felt confident that Service A would be able to act in his best-interest.

MOTHER: *I suppose [Service A]. will do their very best to meet Ben's needs and to look after him etcetera etcetera. So in a way they would be the welfare guardians unless we can find somebody. They wouldn't be the official welfare guardians, but near enough I would say and for financial well it would just be the lawyer I would think. We need to sort this out (turns to her husband). Something else to be sorted out.*

I asked his team leader if she thought the service's role would change if Ben's parents should one day not be there anymore.

SERVICE A: *To be honest we do it all now, I don't see a huge change. (...) We are in touch with all the relevant professionals that are required and every two weeks the staff team review his care at a team meeting so we just put in whatever needs to happen. I don't think, we just continue to be reviewing his support constantly, which we do anyway and as it changes.*

6.1.3 Comparing the transition journeys of study two to those of study one

Themes raised in this study bore similarities to the themes highlighted in study one. Namely: (i) Parents were proactive and started planning for the transition into supported accommodation early and out of their own initiative and (ii) Barriers and concerns were located largely within the wider service provision context. Differently to the first study, transition processes were defined more broadly and there were greater differences between the circumstances and life situations of the three adults. Furthermore, the three transitions into supported accommodation took place at different points in time, reflecting different economic circumstances. Lisa's transition, as the most recent one, might describe a turn to a more crisis-driven practice, as was suggested by parents in the other two cases when discussing their experience of current transitions into supported accommodation compared to their own past experiences. However, caution needs to be given as parents in Luke and Ben's case might have given a more positive account of the transition into supported accommodation because they reflected on the past without recalling or emphasising difficulties or stressors that might have been present at the time.

Looking back across the six transition journeys highlights how transitions are more than just a physical move or a physical change in circumstances. Across the six cases transitions took place on different levels. This included emotional processes of adjusting and coming to terms with change, organisational and bureaucratic practices and practical processes. Additionally, the transition journeys showed that change was a continuous experience for families. Instead of seeing transitions as periods of change that follow and are followed by periods of stability, continuity of change within adult services stood out. In study two smaller changes moved into focus alongside the bigger transition of moving into

supported accommodation. While all parents in study two spoke positively about the current life of their children, worries about the stability of arrangements were prominent. Future uncertainty seemed to affect the quality of life of parents more than the lives of their children (at this moment in time). Having a close and trusting relationship with their child's adult service seemed to be an important factor to help parents worry less.

6.2 Proximity displays study one and study two: Exploring people's support networks and involvement within transitions

In the following I will present the proximity displays that were created with parents and one social care professionals during interviews. The displays were created to get a better sense of the support networks that were present in people's life during the transition. The displays illustrated experiences of continuity and discontinuity in support, highlighting the relationships that ended for the person during the transition. Additionally, the displays explored the involvement of different stakeholders in the transition process. Comparing the displays to each other helped to examine if people who were identified as central to the transition process did know the person and had direct experiences and knowledge about their life. The proximity displays of study one are presented first, followed by the displays created in study two. In the end findings from both studies are summarised and compared.

6.2.1 Proximity displays study one: From school to adult services

During my last interviews with the mothers of Tom, Emma and Peter I asked them to place cards of people around their child, answering the question 'How involved are people in [your son's/daughter's] life?' All proximity displays that were created showed that next to the family, school was a main network in young people's life before the move to adult services. In all cases mothers placed social work and health professionals further away. Although some of them had been involved in young people's life for many years, mothers described that their involvement mainly consisted in occasional visits and social work contact was described as being mainly with parents.

Figure 23: Proximity to young person (modelled on Tom's mothers' display)

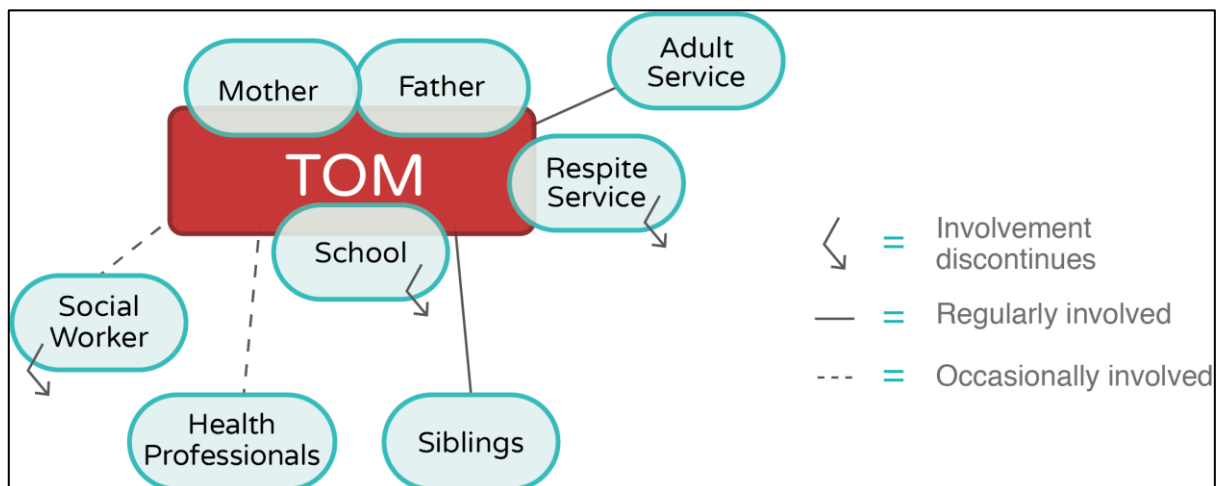


Figure 24: Proximity to young person (modelled on Emma's mothers' display)

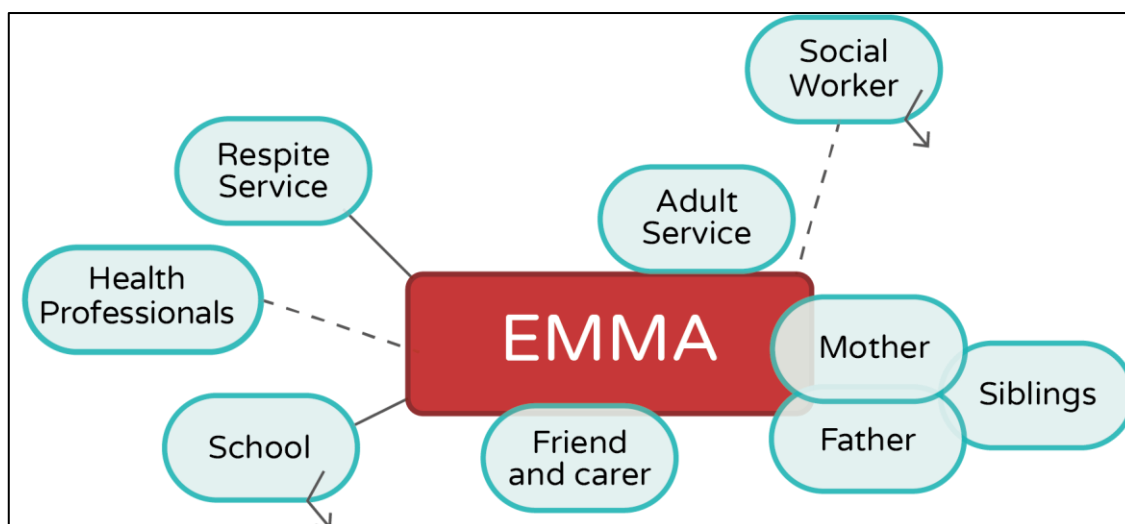
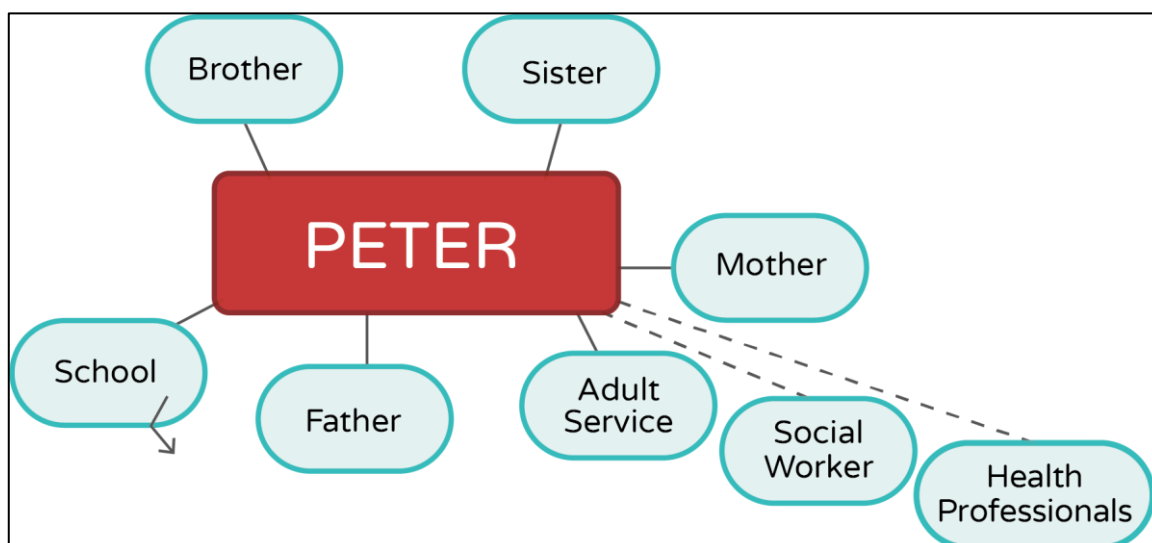


Figure 25: Proximity to young person (modelled on Peter's mothers' display)



Emma and Peter's mother placed the adult service close to their children. Peter had already lived at his new service for a year and Emma's mother placed the adult service close to Emma as she felt that Emma had quickly formed relationships to people. Tom's mother placed the adult service further away as she felt that Tom had just started at the service and was still getting to know staff. Emma's mother was the only one who included someone else in the display. While exploring important people in Emma's life, her mother started to talk about a carer Emma sometimes spend weekends with. This carer was described as a friend to Emma. While Emma's mother talked about her, her appreciation of someone outside the family caring about Emma and taking an interest illustrated how rare this was for the family.

MOTHER: *Emma is as fond of her as she is of us you know what I mean. And that is really special because a lot of the people that are looking after children (...) a lot of it is to do with money. (...) And in the past when I had no respite, when I was having to pay for it, she was, she really, really helped out*

Involvement in transition process

During the second task I asked mothers to place cards, answering the question 'How closely have people been involved in the transition?'. Mothers answered the question differently and emphasised people's proximity to the transition either in relation to practical processes (preparing the actual move) or organisational ones (placement and funding decisions) and this resulted in differences between the transition displays. The task contributed to an important step in my understanding of transitions as different but inherently linked processes. I recognised that in my question to mothers the transition was too broadly defined, unable to grasp different processes involved.

Figure 26: Proximity to transition (modelled on Tom's mothers' display)

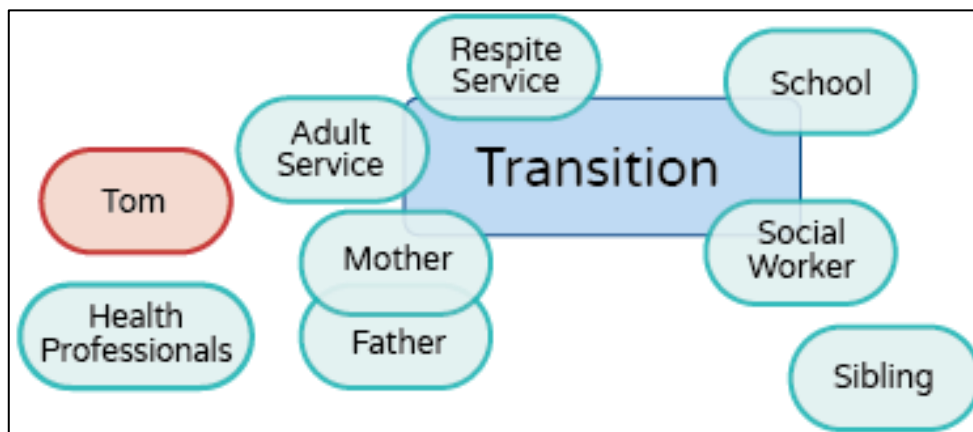


Figure 27: Proximity to transition (modelled on Emma's mothers' display)

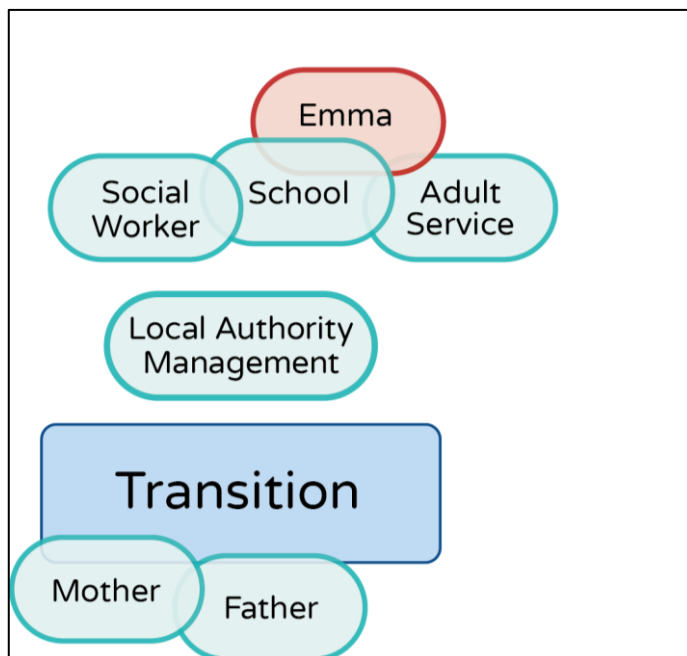
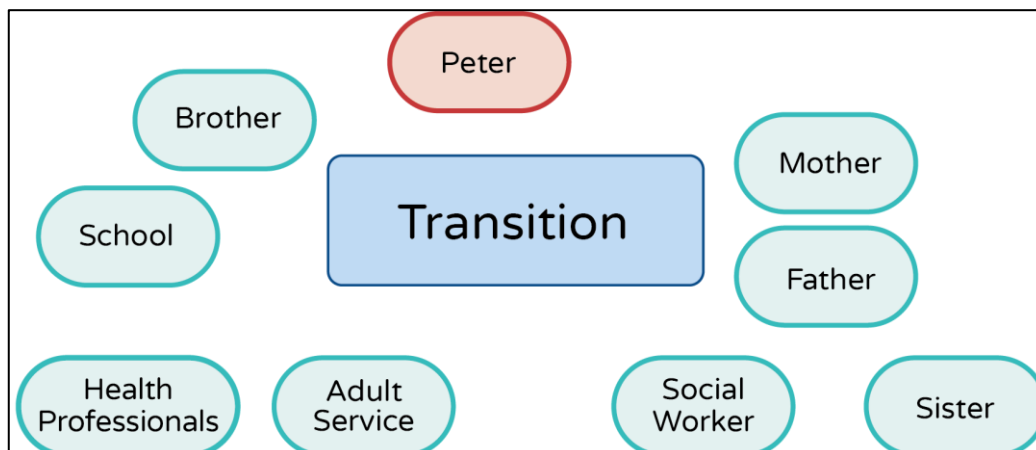


Figure 28: Proximity to transition (modelled on Peter's mothers' display)



Tom's mother focused on the practical transition and how services had worked together to plan the move. Emma's mother emphasised the organisational side of the decision-making process. She placed social work management opposite 'parents', reflecting how she had experienced many parts of the process as a 'fight' with management. Peter's mother created a display that looked very similar to the first one, reflecting how she felt that those close to Peter had all been central to the transition process.

Siblings were included in two of the displays. Peter's mother described how they had involved their daughter in discussions about the transition. In Emma and Tom's case both mothers described how their other children were aware of the process to different degrees but both stressed that they did not want their children to feel obliged to take on caring roles or to feel burdened by responsibility.

Changing the displays: Organisational and practical processes

To illustrate differences in the processes that were highlighted in the displays above (Figure 26, 27, 28), I went back over interview transcripts and changed the displays by mothers. Instead of one I created two displays to highlight differences between people's involvement in: (1) Supporting the actual move from school to the service (practical transition) and (2) The decision-making process on an organisational level involving decisions about budgets and identifying available services (organisational process). The displays of the practical transition and the displays that showed main networks in the life of young people were similar, reflecting that in all cases young people's main networks worked closely together during the practical process. Social workers and local authorities whose involvement was infrequent and who were further removed from the person were more closely involved in the organisational process. This was more striking in Tom and Emma's case than in Peter's.

Figure 29: Proximity to practical transition – Tom's case (created by researcher)

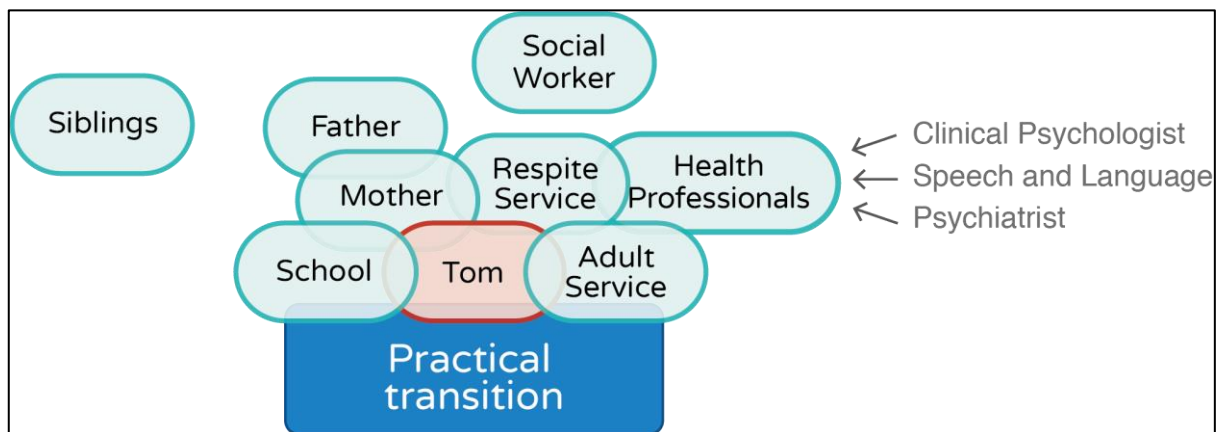


Figure 30: Proximity to organisational process – Tom's case (created by researcher)

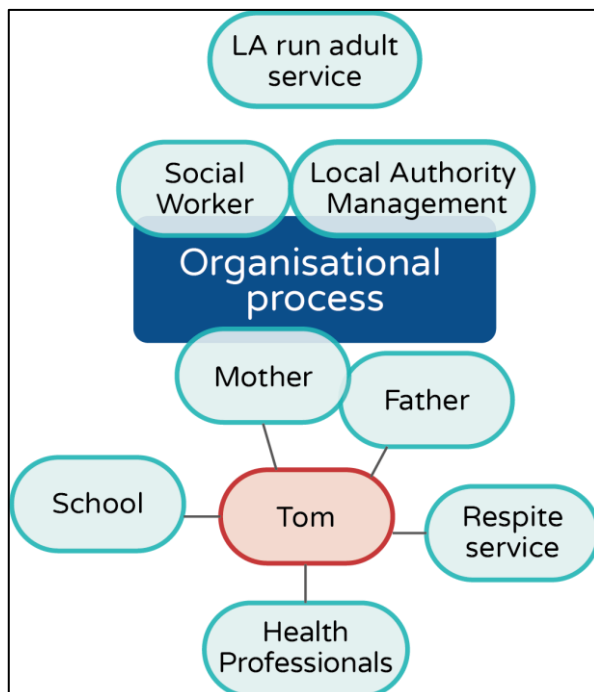


Figure 31: Proximity to practical process – Emma's case (created by researcher)

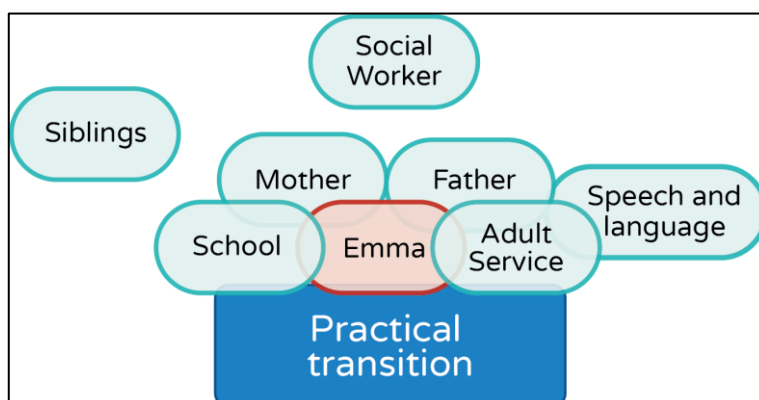
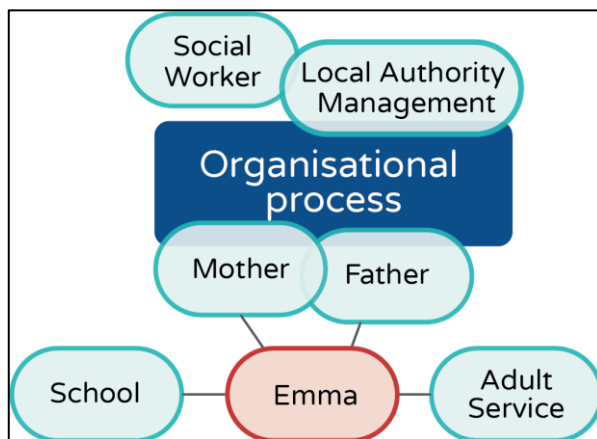


Figure 32: Proximity to organisational process – Emma's case (created by researcher)



In Tom and Emma's case main networks of the young person worked together to support the practical transition. Yet, they had less involvement in the organisational process. School, respite and health professionals were able to give an account of their views, standing 'behind' and 'beside' parents and young people, but they had little decision power. In both cases parents and social work negotiated how to meet the person's needs with that was available in the local area.

In Peter's case both displays showed similarity. People were placed close to each other and to each of the processes. This reflects that in Peter's case his parents were closely involved in both the practical and organisational process. Although Peter's parents were faced with a lack of services in their local area, they were able to take initiative and identify their preferred services, with others supporting their choices.

Figure 33: Proximity to practical process – Peter’s case (created by researcher)

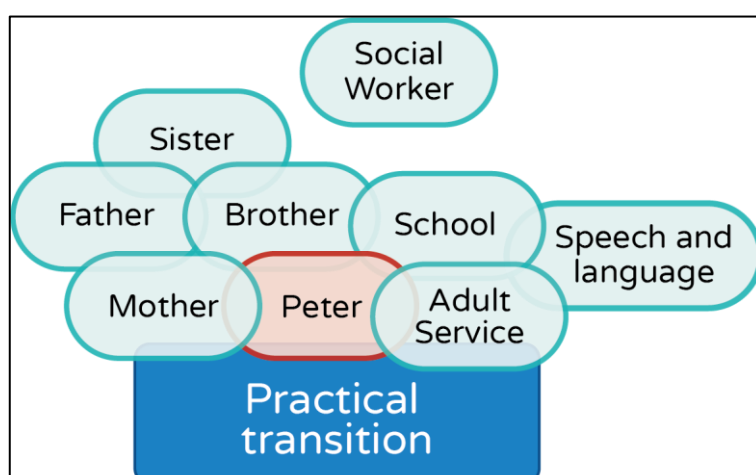
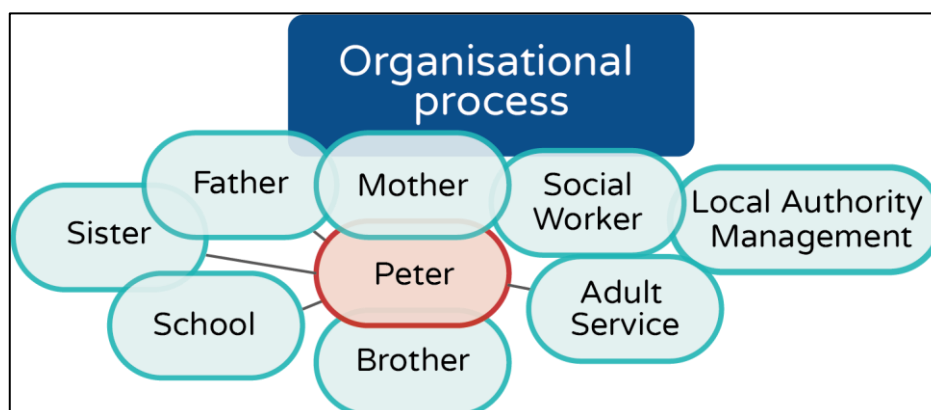


Figure 34: Proximity to organisational process – Peter’s case (created by researcher)



Involvement of Tom, Emma and Peter

I decided to place young people between their main networks to illustrate how those who knew young people well were able to facilitate their involvement or advocate on their behalf. Young people were involved in the practical process through visits and those who knew them well observed their responses to the new setting. Thus, young people communicated their preferences through their behaviour. This was taken into account when identifying adult services, making plans about the move and when deciding on programs and activities. As those closest to the person were more closely involved in the actual move, young people were also placed closer the practical transition, while they were placed further away from the organisational process.

6.2.2 Proximity displays study two: Transitions within adult services

Proximity displays were used again in study two to explore the support networks of Luke, Lisa and Ben, examine continuities and discontinuities in relationships and explore the involvement of people in the transition process. Findings from study one were taken into account and parents were asked to differentiate in their displays between practical and organisational parts of the process. Luke and Lisa's mother and Ben's parents were asked to create displays answering the question 'How closely involved are/were people in the lives of your son/daughter at the time of the transition into supported accommodation?'. The displays showed how the family and support services played main roles in the person's life. Social workers were placed further away in all cases and their involvement was described as infrequent.

Figure 35: Proximity to person (modelled on display created by Ben's mother)

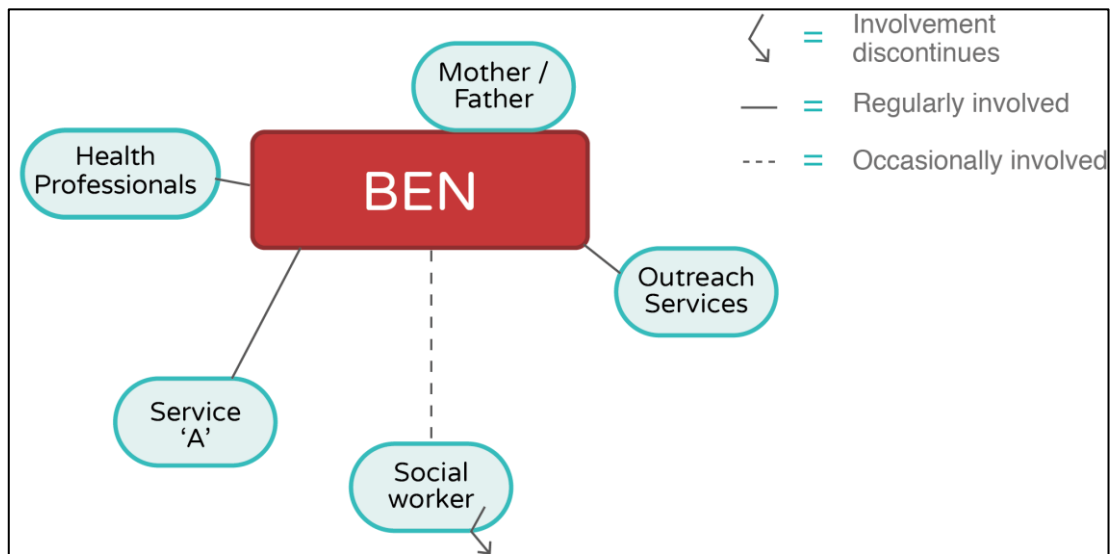


Figure 36: Proximity to person (modelled on display created by Luke's mother)

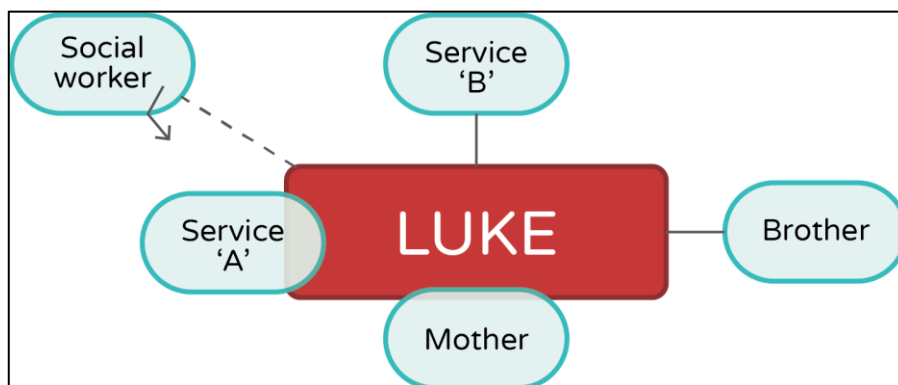
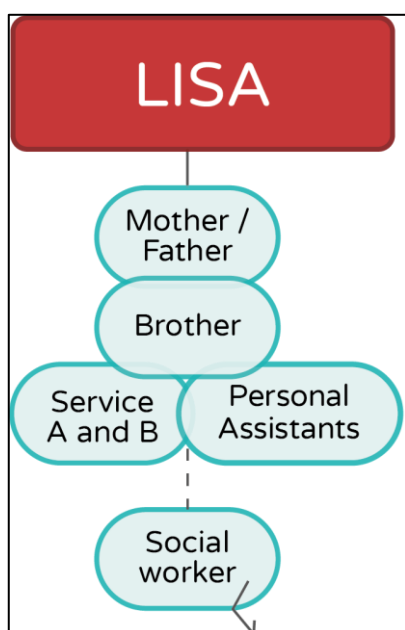


Figure 37: Proximity to person (modelled on display created by Lisa's mother)



Luke and Ben's mother were asked to create two further displays exploring people's involvement in the practical move, as well as the organisational decision-making process (identifying service providers, allocating budgets and making decisions about the timing of the move into supported accommodation). As Lisa was still living at home her mother only created a display to explore people's involvement in the organisational decision-making process so far. The displays illustrate that those who knew the person with severe ID best, were more closely involved in the practical process compared to the organisational one.

Figure 38: Involvement in practical transition into supported accommodation (modelled on display created by Luke's mother)

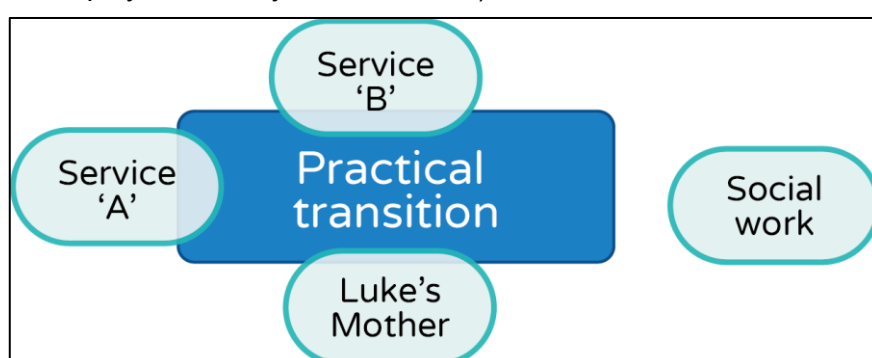


Figure 39: Involvement in organisational process (modelled on display created by Luke's mother)

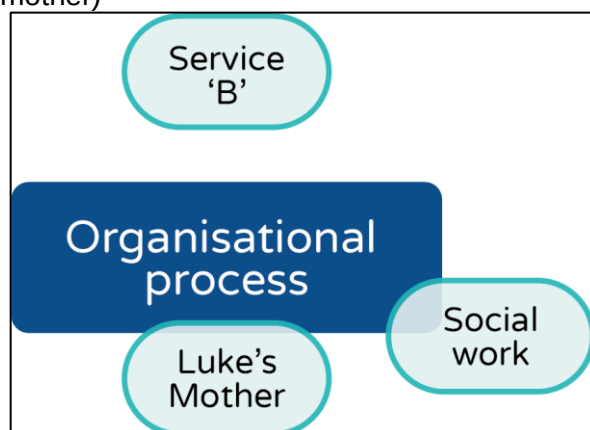


Figure 40: Involvement in practical transition (modelled on display created by Ben's mother)

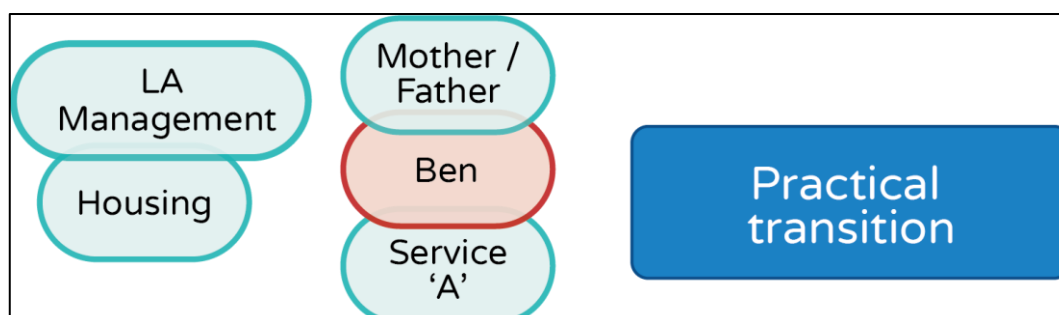
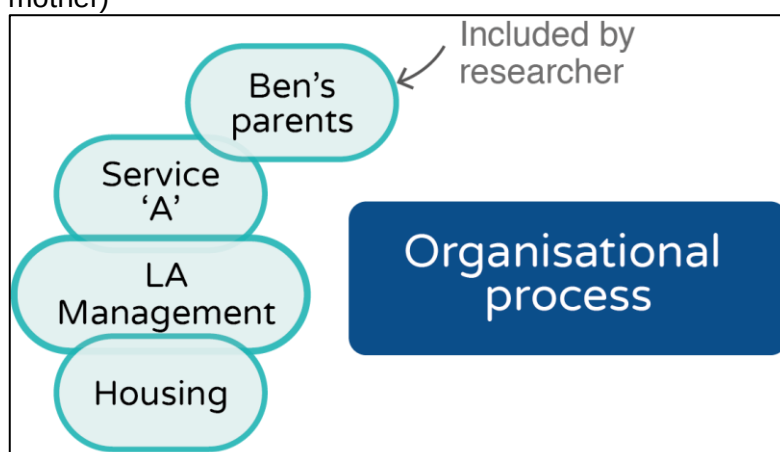
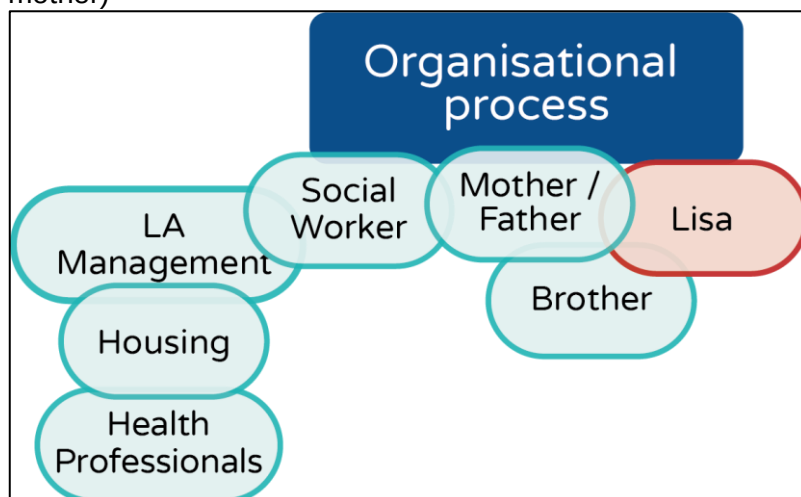


Figure 41: Involvement in organisational process (modelled on display created by Ben's mother)



Looking back over Ben's transition journey I noted how his parents had been closely involved in the process of identifying the service-provider and being involved in the recruitment of staff. Thus, although his parents had not included themselves, I decided to add Ben's parents to the display regarding the organisational process.

Figure 42: Involvement in organisational process (modelled on display created by Lisa's mother)



The three organisational displays showed a stronger involvement of social work, and local authorities compared to the displays about the practical process. Placing social work, housing or local authority management close to the organisational process, parents reflected that the organisational process included discussions and assessments of what would be best for the person, as well as needing to work with what was available at the time. For example, while Ben's

parents had always advocated for a downstairs room, he moved into a house with an upstairs room and lack of housing was a major problem in Lisa's case.

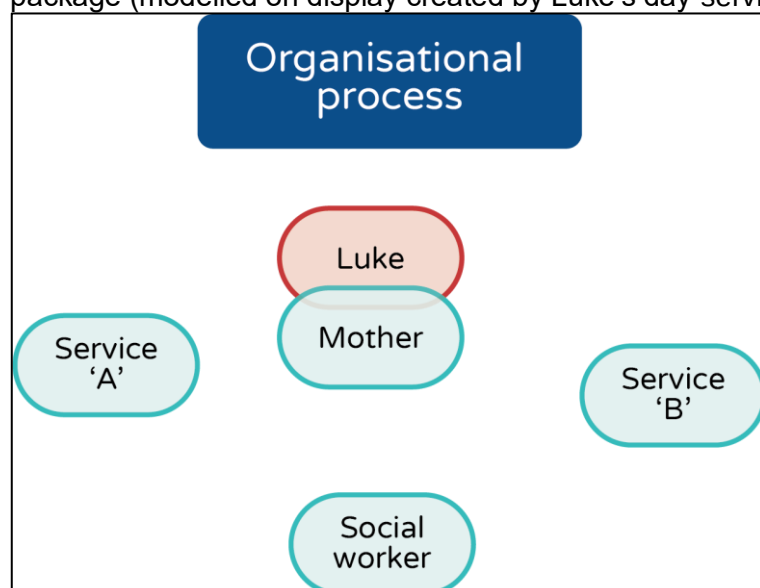
Involvement of Luke, Lisa and Ben

There were interesting differences in the way mothers included their children in the proximity displays. Luke's mother did not include Luke in either of the two displays about the transition, while Ben's mother only included him in the display about the practical process. This seemed to reflect the complexity of how to conceptualise involvement. Although Luke was not included in the displays, throughout both interviews his mother discussed how decisions made were based on Luke's interests, likes and needs. For example, while his mother would have preferred Luke to live in shared accommodation within a social environment, she looked for a single flat as she knew that Luke seemed to find social environments difficult.

LUKE'S MOTHER: *When he was little I always imagined that he would go to a [shared-living community] because I really like the philosophy of that, the inclusiveness and the community aspect, but it just would not have been right for him because he would have been on high alert all the time.*

During my interview with Luke's day service manager I asked her to create a display to explore the involvement of people in the recent process of reviewing his care package and program. Her display gave a central role to Luke.

Figure 43: Involvement in organisation process in relation to recent review of support package (modelled on display created by Luke's day service 2)



She felt that everyone was trying to make decisions based on their knowledge of and engagement with Luke.

LUKE 'S DAY SERVICE 2: *In my head like Luke is top because none of us would be here without him if that makes sense. He is leading the way because he is here. (...) Luke is why we are all here. I think it is important that he is at the top. Maybe that does not make sense to other people though.*

While she acknowledged that social work had a lot of control in terms of agreeing the funding, she also felt that social work took guidance from Luke's mother and both his adult services. Luke's mother had given a similar reflection but felt that it was difficult to conceptualise Luke's involvement due to the difficulty of knowing how much Luke was able to understand. Similarly, while professionals in his adult day service talked positively about using different communication strategies to try and get Luke's view, they also felt that it was difficult to really know.

LUKE's MOTHER: *I think the problem is how much do you do what a person wants, who does not really have capacity to necessarily make good decisions for themselves.*

LUKE's DAY SERVICE 1: *He comes across to people that he understands everything because he says yes and no and he smiles. So that is his social skill but sometimes he does not understand what you are saying. He is just pleasing the person who is asking him the question. But if you actually ask him in a different way he will get stressed and upset.*

Lisa's mother included her in the display, but described that as Lisa was non-verbal she depended on her family to advocate on her behalf.

LISA'S MOTHER: *I have done it her whole life [advocating on behalf of daughter] and it is just a continuation of what I have been doing. There is sometimes the feeling from people who deal with learning difficulties that yes (...) they can have their say and make up their minds and speak for themselves and all sorts of things like that and I think they forget that there are people like Lisa, who do not have capacity to do that, who do not have the words and they will not be able to say these things.*

Her mother described that Lisa was able to communicate her views by expressing how she feels about different environments through her behaviour. Yet, she explained that to do so Lisa needed to have experiences of different settings and, moreover, the people who observe her in these environments and have detailed

knowledge about her everyday-life experiences, needed to be involved in decisions that are made.

LISA'S MOTHER: *She can't say I want to move into my own place and she can't say what exactly she wants. She can only do it by sort of well I think she could only do it once she was there by sort of her mood, gestures and so on (...) I really think the only way she can sort of indicate is when she is actually there.*

I noted down a similar observation during my visit to Lisa's day service. I experienced Lisa as a young woman who was able to communicate what she wanted, but I was also very aware that this required her support staff and people in her life to be finely attuned to her and to find ways to communicate with Lisa about possibilities available to her, which seemed difficult at times, which this vignette from my observation illustrates:

OBSERVATION: *We are going for a walk around the building. Lisa is guiding the way. She stops a number of times to stand still, then lifts her left leg and stamps it on the ground. Mia copies her and Lisa smiles. There is a stone in the way and Mia takes Lisa's hand to help guide her around the stone. Lisa pushes her hand away and moves to the side away from Mia. 'You need to be careful', Mia says. 'There is a stone'. Mia takes her hand again but Lisa pushes it away. She moves forward and her foot touches the stone, she wavers for a moment and then places her foot on the ground. Mia has taken her hand again and this time Lisa does not push it away. Lisa moves her other foot forward. She has stepped over the stone. We have reached the back of the building and are entering again through the back entrance. A music group has started 10 minutes ago. It took us 20 minutes to walk around the building. The room is diagonally across the café and I can hear music coming out through the door. We walk inside the café and Mia tries to take Lisa's hand and to guide her to the music group, but Lisa pushes her hand away. She sits down on a chair close by. Lisa sits on the chair rocking forwards and backwards. 'It is a shame because I am sure she would enjoy going there and being in the room, but how to tell her that it is happening? How to get her there?', Mia says. She goes to the room and gets a set of drums. 'Maybe we can bring the music to you', she says. She places the drum on the table and starts to tap on it. Lisa smiles. Mia moves the drum closer to Lisa. She pushes it away, gets up and sits down on another chair. Mia plays the drum for a bit longer and then stops. Lisa has moved away from us and now sits three chairs away. She rocks forwards and backwards. The music continues to come out of the room. Lisa sits calmly, rocking, smiling, her head is turned slightly to the side. 'I think she is listening to the music', I say. 'Yes', Mia says. 'I think she can hear it and she is listening to it'. (Observation vignette, study two, case two, Lisa, August 2018)*

6.2.3 Proximity displays – summary and reflection

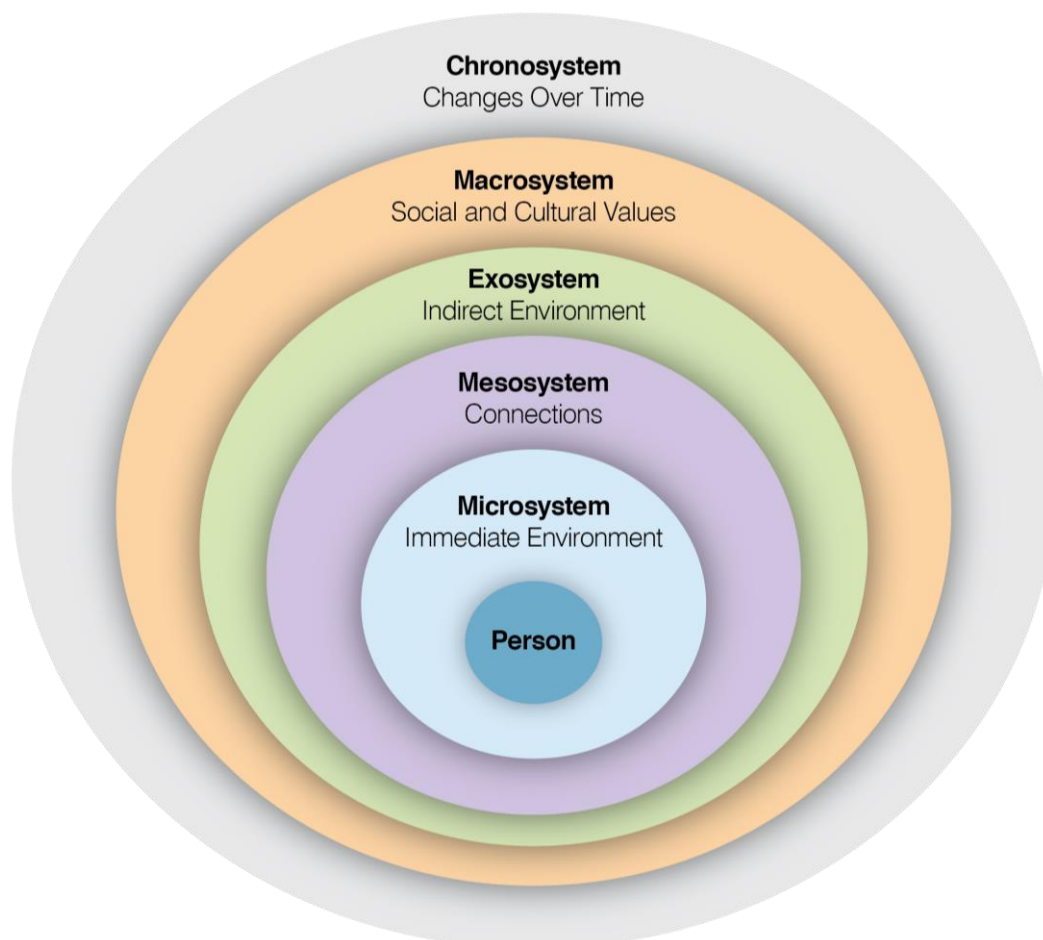
Findings in relation to the involvement of the six adults shared many similarities across the two studies. People's behaviour and responses to different environments helped those that knew them well to interpret their preferences and likes. At the same time the complexity of interpreting people's behaviour into views was acknowledged. Furthermore, the proximity displays helped to differentiate between practical and organisational processes. Professionals that knew the person well were more closely involved in the practical parts of the transition but had little involvement in the organisational process. Additionally, the displays helped to illustrate that transitions were a time when a number of relationships were lost. In all cases, except Luke's case, there was little overlap to allow the person to form new relationships to professionals in their new setting before losing connections to people and settings who had supported them for many years. Furthermore, all families experienced frequent changes in social workers.

In the following, themes about people's involvement in the transition and available support that have been raised here, will be explored further, drawing on all available data sources to synthesise findings across cases in study one and two from an ecological perspective.

6.3 Framework analysis study one and study two utilising Bronfenbrenner's model

Framework analysis was used to explore differences and similarities between Tom, Emma and Peter's transition journeys from school to adult services (study one) and Luke, Lisa and Ben's transition journeys within adult services (study two). Bronfenbrenner's ecological model was applied to the data to explore themes and influences across different levels. Using Bronfenbrenner's model allowed me to unpick how influences across systems shaped the transitions. Themes did not fit neatly into separate ecological levels and close relationships between systems were apparent throughout the analysis (for example, conflict between stakeholders seemed to be influenced by cultural and economic factors). Where themes corresponded to different ecological levels, a choice was made as to where the content would fit best and relationships between systems were observed throughout.

Figure 3: Bronfenbrenner's model



6.3.1 Framework analysis study one: Transitions from school to adult services

An adapted version of this part of my findings chapter was published in the journal *Disability & Society*. The published article can be found in the appendices.

The ecological model that had been developed in the systematic review was applied across data sources. Based on my data the ecological framework was changed and adapted compared to the systematic review (see table 33 and 34).

Tables 33: A-priori framework based on systematic review

Ecological levels	Subthemes
The Family	The young adult Parents Quality of life
Microsystems (Changing Networks)	Ending school Perceptions of adult services Additional networks
Mesosystem (Decision-making and Collaborative Practice)	Choice and information Roles and Relationships Involvement of the Young Person
Exosystem (Organisational context)	Coordination of services Budget and funding processes
Macrosystem (Society)	Culture Politics and economy
Chronosystem	From past to future

Table: 34 A-posteriori framework study one

Master Theme	Subthemes
The young person	Likes, abilities and needs Becoming an adult: changes
Microsystems	Family Professional environment (school, adult service, respite, health) Additional networks
Mesosystem	Practical transition Involvement of young person Roles and Relationships
Exosystem	Organisational transition Involvement of young person Information and Choice
Macrosystem	Culture Politics and economy
Chronosystem	A life-course perspective

Most notably, my data allowed me to have the young person instead of the family at the centre of the framework and young people's likes and needs are discussed within the first system in detail. Correspondingly, the analysis was able to give greater attention to young people's existing networks within the Microsystem. It is suggested that the involvement of young people differs between practical and organisational processes and therefore, differently to the previous framework, the involvement of young people is discussed within both levels. The practical transition is discussed within the Mesosystem and organisational processes are included within the Exosystem. Furthermore, while cultural and political influences were tentatively sketched in the systematic review, this study was able to add more depth to the understanding of influences within the Macrolevel.

6.3.1.1 THE YOUNG PERSON: TOM, EMMA, PETER

This theme discusses how far young people's likes and needs informed choices made before questioning how far the move to adult services also marked a step towards adulthood for young people.

Likes and needs

Parents favoured adult services able to facilitate activities young people seemed to enjoy such as being outdoors, engaging in music, arts and crafts and socialising with peers. However, alongside what these young people liked, their vulnerabilities and associated risks were a central part of identifying an adult service placement. Emma and Peter were both described as highly prompt dependent, with great difficulties to understand social situations and to communicate their own needs. Tom showed an even greater complexity. He displayed frequent and high levels of self-harm and a lot of effort and care was put into meeting his mental health needs.

Tom's Clinical psychologist: *He does need like high levels of support in terms of sort of helping him to make sense, he needs high levels of structure and routine to help him make sense of the social world and also he has very high levels of sensory need as well.*

Becoming an adult: Changes

Tom, Emma and Peter were described as learning and acquiring new skills, this included getting better at using their communication systems or using the toilet independently. However, they were also described as becoming physically stronger and this could lead to new challenges for parents. When Emma refused an activity, such as leaving the car, her mother said there was nothing she could do. Peter was described as cycling and walking faster and for longer distances than anyone else in the family and as Tom was becoming older it was more difficult to manage some of his behaviours.

Participants had different views on how to understand young people's steps into adulthood and in how far the transition into adult services should also mark a change in attitudes towards, and expectations of, the young people. Teachers and adult service professionals seemed to see a more central role of choice within adult services and greater flexibility to create activities and timetables that were

meeting young people's interests, instead of following the curriculum and meeting the needs of a whole class.

Emma's teacher: *I am not trying to say that adult services don't have structure, but you know, but there is, it's if you are being an adult then you can choose.*

For Emma and Peter, further emphasis was given to work activities and practical learning. All parents emphasised their wish for services to encourage the development of skills, and engagement in activities. As well as emphasising the importance of meaningful engagement, interviews highlighted tensions between the notion of 'independence', and accounts that emphasised young people's continuing dependence on adult support. Some professionals connected more independence to the possibility of living in their own flats, fulfilling a step towards 'normal' adulthood, while also describing that to live independently young people would need high levels of support and supervision. Without stable and supportive relationships and environments, a number of participants suggested that young people could easily regress and become more withdrawn. Parents, and some professionals, felt that living in a flat could isolate young people and voiced anxieties about them being dependent on staff and vulnerable to poor quality of care.

Emma's teacher: *I could imagine that she could sit for a very long time if there wasn't that interaction, which I suppose when I think of it, it seems kind of scary.*

Tom's mother: *He is very vulnerable, when someone hurts him, he can't tell us.*

Participants described how young people expressed choices and preferences through their behaviour, but some described a concern that choices did not always reflect their best interest. This pointed to a tension between notions of choice, independence and responsibilities to support young people to be healthy and engaged.

Peter's adult service: *For me independence also shows that he is able to show anything what is really him, his choice. What he would like to do. But then that always needs to be guided within the necessities of life. I mean that he has the right nutrition and I think that it is important that he still has this, the routine to help him with that.*

Emma takes the Weetabix box, a few seconds later she takes milk. She attempts to put three weetabix biscuits into the bowl, 'No just one', her teacher says and puts two back into the box. (Observation vignette, study one, case two, Emma, visit to class, May 2017)

6.3.1.2 MICROSYSTEM

The family, education and social care professionals were identified as young people's main networks. The existence of additional networks, such as friendships or relationships outside the family not including paid employment, were scarce but a number were described and explored within the theme of additional networks.

The Family

The family was the main and central support system for young people. Interviews with all stakeholders highlighted close and loving relationships between family members. Parents spoke about their love for and commitment to their child. Needs of parents and children seemed to be closely intertwined. For example, wanting supported accommodation for Emma was partly based on her parents' experience of getting older and feeling that they would like to have more space for themselves at this stage in their lives.

Emma's social worker: *Because families they are not just want to go to the pub on a Saturday, they are saying I just would like to have a bath or read a book or just sit here and do absolutely nothing.*

Parents described that caring for and advocating on behalf of their children to ensure good quality of care was demanding at times. Parents were aware of their own aging and how it was impacting on their ability to provide care for their adult children now and in the future. However, it was striking that parental wishes for the transition to adult services in relation to their own needs as carers were always concurrently discussed by parents in light of the likes and needs of young people. Tom's mother for instance hoped for a placement that could provide extensive day and respite services, allowing Tom to live with his family and to provide continuity. In the other two cases parents reflected on their children still being young adults and wished for an initial young adult placement before considering 'settling their children'. Tom seemed to express through his behaviour that he enjoyed being at home most, while both Emma and Peter

enjoyed social interaction and being busy and engaged, reflecting a focus on young people within the choices made by parents.

Peter's mother appeared the most positive and talked least about the negative impact of having a son with a severe ID. This might be due to him being the only participant living outside the family, an absence of challenging behaviour and/or him being very content at his current placement. Living in a residential setting didn't seem to be connected to less emotional closeness between Peter and his family nor negatively affect communication between staff and parents. Peter's transition process had occurred a year ago, thus the day-to-day stress of transition was not present at the time of conducting the interviews.

Mothers seemed to play central roles. However, the inclusion of the father's perspective in Emma's case highlighted similar concerns and levels of stress and worries for him to those of mothers.

Emma's father: *I was worried about what was going to happen to her and I was waking up and by the time we got to that meeting I was wiped out, I was completely exhausted.*

Fathers were involved in meeting with professionals and caring for young people at home, but mothers were described as main carers, with fathers spending more time at work. In all three cases taking care of their children had impacted on mother's ability to sustain a full-time job. Parents spoke about siblings as providing important relationships to the young people. In all cases, one of the siblings took on a more caring role as they entered young adulthood themselves, which parents stressed was voluntary.

Professional environment

Overall, parents spoke positively about the support provided and the care offered to young people within care and education settings. Most participants described consistent and trusting relationships to key members of staff as important for young people. There was variation reported in the consistency of relationships: while some professionals had been involved in young people's lives for more than five years (e.g. Peter's teacher, Tom's respite key-worker, Emma's class helper), others had only recently become involved. Staff turnover was mentioned as a problem by both education and adult service professionals.

Health professionals were described as offering important, specialist input, but their direct contact with young people was less compared to education and social care professionals. Social workers' roles differed. They all met young people in different settings but their contact was described as being mainly with parents.

Additional networks

In all three cases it was difficult for families to draw on the support of their extended family, and the immediate families seemed to draw on different support networks. Other parents with children with disabilities were described as a source of support only in Tom's case. Additionally, a close family friend supported the family in an advocacy role. In Emma's case, one of her paid carers was identified by her mother as someone 'special', who cared about Emma and helped out on occasions. She was described as being like a friend to Emma.

All participants talked about the importance of close relationships generally but only eight mentioned peers and friendships (Tom's adult service and teacher; Emma's mother, teacher and social worker; Peter's mother, adult service and social worker). There were differences in participants' accounts about the role of peers and friendship. While Emma's social worker and both Emma's and Tom's teachers raised doubt about young people's abilities to form friendships with peers, the eight interviews also included accounts of existing friendships and important interactions with peers.

Tom's adult service: *There is a young man who comes to [our service] who was in Tom's class last year and they seem very friendly it is nice. Tom seems to have sort of a calming effect on [him] and [he] can offer Tom lots of cuddles. Often Tom goes up to [him] for a cuddle, which is lovely. That must be reassuring for them both to come into the service and have a familiar face.*

6.3.1.3 MESOSYSTEM

The Mesosystem examined relationships between people's immediate environments, how networks worked together to support the practical move and in how far young people were involved in the process.

Practical transition

The practical transition was described as positive for all three young people, with good communication and sharing of practice between stakeholders. A disparate health transition to adult mental health services was an issue in Tom's case and was anticipated to happen after the age of 18. Although parents and professionals did meet at annual or bi-annual review meetings, there was no single meeting where all stakeholders came together. Review meetings at schools seemed to focus on initial plans about possible placements and adult services did not take part in meetings at this stage.

Lack of transport was identified as a potential problem in both Tom and Emma's case and while arrangements were made to find a solution by Tom's social worker, Emma's parents experienced a lengthy struggle to get funding for Emma to travel to both her respite and day service.

Involvement of young person

Participants felt that young people had very little involvement in the transition process. This may be because, for participants, choice seemed to be conceptualised as actively verbalising choices, which was not possible for the young people. However, other parts of the interviews illustrated that young people were involved in the practical transition because they expressed how they felt in different environments and communicated their needs through their behaviour. All young people started to visit their new adult services before the move and this gave parents and professionals an indication about the suitability of services. Only Peter visited two other similar residential adult services through his school as part of the transition process. Participants described how young people's need for routine and consistency played a central role in this decision. A number of participants (Tom's head teacher and teacher, Emma's social worker, Peter's adult service and social worker) referred to the limitation of only being able to make choices based on knowing young people in their present settings.

Peter's adult service admission 2: *I mean at that age you have been used to something and you actually manage extremely well and are very happy within that and an alternative of, for example, living in a flat within*

the community, I mean who is to say whether or not that would be appropriate for him. I wouldn't know. It is based upon how he is just now.

The move to the new setting was described as positive and all young people seemed to be doing well considering that the transition involved a major change in environment and routine. Young people were described as participating in activities, following their new routines and positively interacting with staff.

Collaborative practice: Concord and conflict

Parents and professionals seemed to have positive relationships and problems seemed to relate to limitations such as funding constraints or lack of services. For example, parents were able to differentiate in the interviews between working with social workers and appreciating their work and effort but feeling frustrated to work with the 'system' they represented.

Emma's mother: *I think the social worker had a really difficult job because her hands were tied, completely tied.*

Social workers and local authority managers reflected on limitations within the system and spoke about their own frustrations.

Local authority manager 2: *Local government in terms of finances get tighter and tighter and tighter, so the message is that we need to do things differently to make sure there is money in the system.*

Social workers and local authority managers made reference to the decision-making process being governed by person-centred practice and approaches. However, references were made simultaneously to constraints within existing budgets and reference was also made to the need 'to share resources with everybody'. All parents showed an understanding for the need to share resources and that there was a limit to the funding available. However, parents argued that the inflexibility to respond to individual situations had the potential to create more expensive packages later on. For example, Tom's mother felt that with more respite they could continue to support Tom at home and Peter and Emma's parents believed that shared accommodation was not only more beneficial to their children it was also more cost effective than single tenancies. While professionals needed to work within existing rules and structures, parents were able to fight and to push against some barriers (e.g. Emma's parents succeeding in getting Emma's transport funded by the local

authority). The role of parents as advocates for their children will be further explored in the involvement of young people within the Exosystem.

6.3.1.4 EXOSYSTEM

The Exosystem examined external influences to the transitions. This included organisational processes, available resources and an examination of the role of parents as advocates.

Organisational transition

Families and young people seemed to have very little involvement in 'wider' decision-making such as deciding when transition planning should start and being involved in the kind of services available to them. Those decisions seemed to be shaped largely by existing service delivery and available budgets. It seemed that everyone, from parents to social workers and local authority management, felt that their possibilities were limited by strategy and budget decisions that were made 'higher' and which they were unable to influence.

Local authority manager 1: *The budgets are made in Westminster or they are made down in Holyrood [UK and Scottish parliaments]. (...) If it continues to decrease it will present us with, well it already is presenting us with real challenges going forward. I don't have the answer to that question yet.*

Emma's social worker: *We are more in a corporate sort of world and environment and it is, if you are an old school social worker like me it is really not great (...) if you feel like you are fighting a system.*

Adult service providers reflected on their dependency on having agreed funding in place before being able to recruit staff and plan the transition. Furthermore, the high demand they experienced also resulted in them being dependent on current service-users moving on and having their funding confirmed. A picture emerged of trying to be person-centred as best as possible within the existing constraints of the 'system'. This tension was particularly visible in the narratives of Tom's mother and his social worker.

Tom's social worker: *You know we might have limited resources and what Tom can access just based on his needs or based on the provision within the city but it is still about you know within these limits it's about making sure we have what's best for Tom at all times. And I hope that is what we have done. I feel like we did but I guess time will tell.*

Tom's mother: *There is no individual criticism. It is just the system fails to recognize there are certain individuals that are such hard work that they don't fit into a budget and he is one of them.*

Information, resources and available services

In all three cases, parents started to think about and plan the transition three to two years in advance. Parents felt that there had been little information and support available from professionals at those early stages and parents relied on themselves to find out about available services. Parents and professionals described a lack of local services for young people with high dependency and complex needs and existing services seemed to operate at full capacity. Tom and Emma lived in a local authority with a relatively greater choice of services, yet there appeared to be a lack of services for those with complex health care needs and challenging behaviour.

Tom's social worker: *There is a lack of support services for people with complex behavioural needs absolutely. Complex personal care needs absolutely.*

Parents and professionals preferred local services, as this enabled young people to stay close to their families. Yet, there was an awareness that local services were not always able to meet people's need. This resulted in an out-of-area placement in Peter's case. For Emma there seemed to be more choices, but her parents experienced a lack of 'meaningful' services, as they did not want a 'babysitting' service. In her case the families' preferred a service that was more expensive and not covered by the allocated budget resulting in a decrease in respite for Emma and her family.

Involvement of the young person: Parents as advocates

In all three cases parents were strong advocates on behalf of their children and were able to put their concerns forward. However, although individual concerns and wishes were able to be expressed by both parents and professionals, this did not necessarily lead to any changed outcomes. For example, Tom's severity of need was acknowledged by everyone and education and health professionals voiced their concerns about the respite reduction. This seemed to have an influence on a placement being offered to Tom in the local authority run day and respite service, which had limited spaces, but his respite allowance still reduced

significantly. In Emma's case, everyone who knew her well-talked about Emma showing through her behaviour that she was ready to live outside her family and although this was highlighted in her social work assessment, it did not seem to be an option in the near future due to a lack of accommodation services. Within the Exosystem available resources seemed to shape the process to a large extent. Fighting for young people and their own right for support resulted in stress for parents.

Emma's mother: *I mean it is not about the money it is about the principle I think. But every little step brings more problems with it, if you know what I mean, because it is just another anxiety and they know that, so they know that people will get fed up with fighting.*

6.3.1.5 MACROSYSTEM

This theme explores perspectives and beliefs about the inclusion of people with severe ID in society, as well as the political and economic context, highlighting a gap between the ideals of policies and actual practice.

Culture

Parents and professionals made references to their experiences of changes within the culture and values of service delivery and attitudes to those with ID in society over past decades. The move away from segregated settings was described as a significant shift in the care and inclusion of people with severe ID in society. However, parents and some professionals (all education professionals, Peter's adult service and Emma's social worker) discussed how they felt that the closure of day services and funding cuts since the beginning of austerity had resulted in a decrease of possibilities for people with severe ID and that policy values such as inclusion, choice and person-centeredness were not reflected in the services and resources available to families.

Peter's adult service admission officer (2): *The difference between the reality and what is being presented and what is said has never been as wide as it is now ever since I am involved in this work and that is forever. So I have never known a time like this. I think it is really, really desperate.*

Involvement and engagement within local communities were important for those that knew young people well, but especially parents and adult service staff who highlighted the importance of meaningful inclusion in contrast to

'babysitting'. Art, music and workshop-based activities were mentioned as good examples to achieve meaning within activities. Access to nature and to public facilities, such as libraries or sport activities, were cited as other examples.

Emma's mother: *I don't want to see her wandering around with some carers on the phone (...) to get something to eat. I want her stimulated.*

Politics and economy

National policies, promoting person-centeredness and individualisation, seemed to describe 'the ideal scenario', while local authority documents and interviews with managers pointed more to limits within service delivery, describing a shift towards providing less services. There thus seemed to be a tension between conceptualising choice as what families ideally liked and choices being inherently linked to what was available. For example, in Emma's and Tom's case parents were told that choosing a more expensive service would involve a decrease in respite. Parents therefore talked about how their choices felt limited, while local authority managers described that it was families who ultimately made the choice of what they would like.

Tom's mother: *I didn't feel there was any room for manoeuvre at all. Sadly.*

LA manager 1: *So basically if they can do it for five days at that provider but they want five days with this provider, which they can't afford, sorry that is your choice.*

In both Tom and Emma's cases, the local authority respite policy played a role in the decision-making process. Both young people transitioned to adult respite service on their 17th birthday and not at the end of their school years, leading to difficulties as families were faced with two disparate transitions (from school to adult services, and from child to adult respite). Both families experienced a decrease in support within adult respite services, with Tom's family experiencing a significant drop. A decrease of respite support in adult services, while needs of young people remained high, was incomprehensible for parents.

6.3.1.6 CHRONOSYSTEM

Taking a life-course perspective highlighted that the three transitions were closely connected to families' past experiences of working with professionals and hopes and worries about young people's future.

A life-course perspective

Narratives of parents were framed within reflections of past experiences, going back to their children's diagnosis and early education experiences, and in anticipation of the far future and worries about their own aging. What stood out in the transitions of all three young people was that, after the transitions, many questions and concerns about the future of their children remained for parents. In interviews with all three parents, once the transition to the new adult service was made, issues and questions that had concerned parents in the beginning of the present transition started to be raised again and they talked about a lack of information on what would happen next. In Peter's case his placement was coming to an end at the age of 25 and issues were raised around a lack of local services. Emma's parents were still looking for a placement outside the family but were anxious that this should not impact on her being able to access her day service. Tom's mother hoped to have found the right place for Tom to settle but wondered what would happen if she found the family was not coping with the reduced respite. Losing the involvement of the transition social worker and not having a new named person worried her. While all participants reflected on the near adult future of young people, parents were the only ones who explicitly talked about the transition in terms of planning for a time when they would not be able to look after, or advocate on behalf of, their children any longer.

6.3.1.7 Concluding remarks

Applying Bronfenbrenner's ecological model helped to carve out different processes and levels involved. Using an ecological lens highlighted that the support available for young people to move from school to their new setting described a more practical transition, while decisions in relation to funding and access to services related to structural processes that began earlier and continued after the move. Tensions were identified within and across ecological levels. The wishes and needs of young people, as identified by those close to

them, could not always be met due to a lack of available resources and organisational barriers within the Exosystem. Detailed knowledge of young people's everyday lives was present within the Micro- and Mesosystem, while there seemed to be less of a connection between knowing about young people's likes, wishes and needs, and influences and decisions made within the Exo- and Macrosystem. Professionals that were close to the person had minimal involvement in the earlier stages of the transition process and available resources and existing structures seemed to shape the process to a greater extent. Additionally, while practice guidelines in Scotland recommend that transition planning should be available from age 14 and should continue to at least age 25 (Scottish Transitions Forum, 2017), the timelines of the three cases show that detailed and involved planning happens later and in Emma and Tom's case the involvement of the transition social worker stopped once the transition was made, while Peter was approaching a further transition at the age of 25.

Drawing on the views and experiences of different professionals highlighted how all stakeholders felt that their choices were limited by available resources. Furthermore, the examination of multiple perspectives showed differences in conceptualisations of the transition as a step towards adulthood. There seemed to be differences between conceptualisations that linked adulthood to independence, autonomy and an absence of support, compared to a more a relational understanding that valued consistent and supportive relationships in young people's lives now and in the future.

6.3.2 Framework analysis study two: Transitions within adult services

The ecological framework from study one was applied to the data across the three cases in study two. A number of changes were made to the framework. Overall themes had a stronger focus on people's lives within adult services. While the transition into supported accommodation was the focus of the analysis, themes also emphasised subsequent smaller changes and descriptions of Luke, Lisa and Ben's adult lives more generally. Within the Exosystem, advocacy was extended from a focus on parents, to also include adult services as possible advocates. The Chronosystem continued to focus on the question of who would care for and about the person once parents would be unable to do so, but also included reflections on past, present and future models of service provision.

Table 35: Framework study one

Master Theme	Subthemes
The young person	Likes and needs Becoming an adult: changes
Microsystems	Family Professional environment Additional networks
Mesosystem	Practical transition Collaborative practice: Concord and Conflict Involvement of young person
Exosystem	Organisational transition Involvement of young person: Parents as advocates Information and Choice
Macrosystem	Culture Politics and economy
Chronosystem	A life-course perspective

Table 36: Revised framework study two

Master Theme	Subthemes
Adulthood: Ben, Lisa and Luke	Life within adult services Being an adult
Microsystems	Family Professionals Additional networks
Mesosystem	Practical transition Involvement of person Collaborative practice
Exosystem	Organisational processes Involvement of person – Advocacy
Macrosystem	Politics and economy – The policy gap Culture
Chronosystem	Future responsibility – Who will care?

6.3.2.1 ADULTHOOD: LUKE, LISA, BEN

This theme will discuss the lives of Luke, Lisa and Ben within adult services and how participants conceptualised adulthood.

Life within adult services

All in all, family members and adult services described the quality of life of Luke, Lisa and Ben as good. However, interviews with family members also highlighted the risk of this to change any time. Families' had needed to work with social services and engage with formal structures throughout their children's lives. This brought uncertainty to the lives of families, as parents and their children always depended on 'the system'. Parents talked very positively about the current life of their children, while at the same time expressing feelings of worry and concern about the future. This was the most apparent in Luke's case. He was making

progress at college and was engaged in music and art projects, at the same time his life was at risk of becoming restricted should further incidents occur.

Luke's social worker: *His mother's worst fear is that he has to go into the [psychiatric hospital] or some restricted closed type of environment and I suppose that could happen.*

In Lisa and Ben's case parents voiced concerns about the possibility of their children's health deteriorating, but similarly to Luke's case, their biggest fear was that their children would become isolated, unable to access activities and socialise with others in the future.

Ben's mother: *They got to have a purpose. If they are just sitting in a chair all the time and they do nothing, they are just going to get worse and worse and worse, going to end up in hospital.*

Parents described how music, art, movement and social groups offered meaningful activities for their children, but that it could be hard to find suitable groups. Parents financed many of those activities privately.

Being an adult

In both Luke and Ben's case participants spoke about the importance for adult services to promote choice and ownership. To promote ownership Ben and Luke were involved in looking after their home and doing daily tasks such as hoovering or preparing meals. Choice was discussed in all cases. While choice was seen as integral to adulthood, participants reflected that it could be difficult to interpret people's behaviour as choices. For example, in all three cases participants discussed that the refusal of certain tasks or requests for certain foods, could not simply be translated into choice. Participants felt that the right to choose needed to be balanced with the promotion of active and healthy lifestyles. Participants reflected that it was important to expose Luke, Lisa and Ben to new activities and environments more than once to get an indication if they enjoyed an activity.

Ben's adult service: *If it is just once and it goes horribly wrong, he could just be feeling rubbish that day. Dead tired, having an off day like we all have. Try something two or three times, if it is not going well after three times, I think you should just knock it on the head. So, he is able to have choice in that way but you are going to facilitate it.*

Interviews across cases included both descriptions of the person changing, as well as referring to a continuity of support needs.

Luke's mother: *He is better, so much better than he was when he was little, but I think we also have learned how to handle him. (...) At [his day services] he gets upset if it is the wrong support worker with him because somebody is off sick or something, and we see that actually he still is really autistic underneath it. It is just that we accommodate him the rest of the time.*

6.3.2.2 MICROSYSTEM

This theme will discuss main networks and relationships present in the lives of Luke, Lisa and Ben.

The Family

Within adulthood parents continued to play a central role in the lives of their children. As Lisa still lived at home her mother was her main carer, supporting her at night and during the day. In Luke's and Ben's case, parents had less daily involvement, but in both cases parents visited their children weekly and Ben and Luke regularly went to visit their parents at weekends and during holidays. Both mothers described how they had needed to adjust to not being their child's main carers any longer and that it had involved feelings of relief and loss.

Luke's mother: *When it is time to go, he is out of the door, there is no hanging about, having a cuddle carry on, he is just ready to go (to his home). So sometimes you sort of think does he actually really care at all? (...) It is a funny conundrum, you want them to love you, but not too much that it means that they can't be by themselves.*

All parents continued to be closely involved in their children's life on an organisational level. Parents were involved in finding suitable activities for their children, organising medical appointments, getting equipment, organising training for staff, recruiting staff and managing their children's finances. Looking into the future, parents saw their roles in the lives of their children changing. Parents felt it was important to step back and to put systems in place that would enable their children to be less reliant on them. At the same time parents seemed to struggle to find others who could commit to caring for their children in the future. This will be explored in more depth within the 'Chronosystem'. While Ben was an only child, both Luke and Lisa had an older brother. Luke's brother had been living abroad for some years and therefore he had limited involvement. Lisa's brother had a more active role. He saw Lisa regularly, was registered as one of her

guardians and had started to attend meetings with professionals to support the transition into supported accommodation.

Professionals

Interviews described close and consistent relationships with a number of social care professionals. The importance of consistent relationships was highlighted to allow staff to get to know the three adults and become attuned to how they communicated and expressed themselves, as well as allowing Luke, Lisa and Ben to become familiar with staff.

Lisa's brother: *For example [certain staff member] still looked after her for several years and I think they both know what to expect from each other. (...) With [her] she already got the rapport. She knows what the script is.*

Social workers got involved when there was a need to review care packages or respond to changing needs and their main contact was with parents. In Luke and Lisa's cases mothers described numerous changes of social workers within their children's school and adult years.

Lisa's mother: *We had a Locum social worker and then we had another lady, she was then off ill at the time Lisa was leaving school and someone else sorted out the various direct payments etcetera and then eventually X was allocated to us and he is unfortunately off sick now, so now we have another lady.*

Luke's mother remembered an involvement of seven different social work professionals since Luke had moved to adult social work.

Additional networks

All three adults were part of local community groups, which offered possibilities for social interaction. Friendships were mentioned in all three cases. Lisa regularly spent time with a group of other adults with profound ID. Sometimes Luke met young people from his day service for lunch and he interacted with peers at college. Ben was described as meeting friends through his local community groups. In all cases the role of staff and families to facilitate those relationships was highlighted.

Ben's adult service: *If you are trying to help two people to come together as a friendship and neither has verbal communication and they both have significant learning disabilities you are facilitating it, which is*

hard to facilitate cause you are the one who is bringing it together and doing the talking.

Lisa's mother: *I think she is aware that they [peers with profound ID] are there, but it is not, she wouldn't particularly communicate with that person. She really needs someone who can communicate with her.*

Luke's day service 1: *At college the feedback was that although he does not really communicate in class with others, at down time he was playing table tennis and stuff with them so it was a nonverbal way of friendship.*

6.3.2.3 MESOSYSTEM

This theme will reflect on the move into supported accommodation and will discuss the involvement of Luke, Lisa and Ben and collaborative practice between families and professionals. While the focus is on the transition into supported accommodation, the theme will also discuss subsequent changes, which were highlighted in the cases of Luke and Ben.

Transition processes – big and small

In all three cases, parents started to think about the move into supported accommodation around the time of their children leaving school. Experiences of available support and information were different in each case. While Luke's mother described the process as straight forward, Lisa's family felt that the process was slow and unclear. Ben's family felt supported by social work and their preferred provider but the process took over two years due to a lack of suitable housing. In Luke and Ben's case subsequent small changes became more central to the analysis and transitions and change were described as an ongoing part of the lives of families and their children. Parents and services needed to respond to the changing needs of Luke and Ben, as well as to organisational changes such as staff turnover, building work, activity groups stopping or changes to funding.

Ben's adult service: *(His epilepsy) is forever changing and we are forever analysing it and we think we have cracked and understood and then it changes.*

Staying on top of 'smaller' changes required close collaboration and communication between parents and social care professionals to ensure that Luke and Ben continued to be well supported.

Involvement of person

All three adults were described as communicating their needs through their behaviour. Their preferences and needs were taken into account when looking for suitable accommodation and when thinking about programs and activities. For example, Lisa was described as preferring busy and social environments and her family wanted her to move into shared accommodation; whereas Luke was described as sensitive to noise and struggling with unpredictability, therefore living in a flat by himself was deemed more appropriate. The way the three adults processed information influenced how they were involved in changes. For instance, in Luke and Ben's case participants stressed the importance of communicating about the move into supported accommodation by visiting the house/flat beforehand, or in Luke's case using social stories. Yet, particularly in Lisa and Ben's case, participants reflected that it was difficult to say how both would react to an environment they had not been in and that one could only truly know by observing their responses to their immediate environment. As their exposure to different environments was limited, it was difficult to anticipate how they would adjust to new settings.

Lisa's mother: *I think the only way she can sort of indicate is when she is actually there.*

In all cases participants talked about involving the person in everyday decision-making. Trying out different activities and approaches, taking time to communicate what was happening, giving the person opportunities to have different experiences, and being attuned to their responses were highlighted as good practice.

Collaborative Practice

In all cases local authorities had nomination rights to decide who was eligible to receive housing and support, meaning that parents needed social work funding before housing and providers could be confirmed. Parents had their preferred providers and both Luke and Ben were supported by services that parents had wanted and identified beforehand. Once a provider, place and support package had been agreed upon, social workers worked with adult services to write risk

assessments and agree support plans. Multi-agency review meetings took place where information was gathered about the likes, needs and abilities of the person. In both Luke and Ben's case, adult service professionals reflected on the importance of having detailed information about possible challenges in behaviour or difficulties staff might be faced with.

Relationships between parents and professionals were described as good but tensions were identified in Luke and Lisa's case in relation to turnover of social workers, lack of communication and slow responses to address concerns.

Luke's mother: *I mean at the moment we are going through this horrendous thing with trying to sort out his funding, which is still ongoing which has been ongoing for nearly a year now. And it is really horrible and stressful.*

6.3.2.4 EXOSYSTEM - 'IT IS ANOTHER LAYER' (Luke's mother)

This theme will continue to explore the transition into supported accommodation, subsequent changes and in how far Luke, Lisa and Ben were involved in both from an organisational perspective.

Organisational processes

All participants spoke about difficulties to find vacancies within supported living services and a lack of suitable housing. Places were in high demand and vacancies in newly commissioned services were filled quickly.

LA Manager: *If we have an idea of how many people we should be delivering the service for, we can look at commissioning from a global perspective. We can flag it up that we need another so many properties in five years time. The level of demand is becoming greater. That is in an ideal world and I need to say to you, the challenges that we face with austerity basically thumb that formula on the head.*

Providers and local authority professionals discussed that they were seeing an increase in demand, partly because parents were looking for supported accommodation for their children earlier than in the past.

Almost all participants (except the LA officer and two professionals in Luke's day service) mentioned how budget cuts under times of austerity had resulted in a

change from long-term planning towards a process driven by crisis and risk management. Additionally, difficulties to recruit and retain social care staff influenced what services were able to offer.

LA Manager: *Are they in a position that they need to be considered for accommodation right now or can it wait until the future. It is based on the principle of risk.*

Provider in Lisa's local authority: *We would advertise and we get lots and lots of applicants in (...) but nowadays it is really poor. I think the standard in the last say five, six years has dropped in social care.*

The local authority manager of Ben's local authority reflected that funding constraints had led to the development of new service models that tried to operate more cost efficiently, resulting in staff working on their own with less supervision and training.

LA Manager: *I firmly believe that there is a lot of models that we are looking at nowadays that care providers are implementing simply because they are a necessity to mitigate the financial austerity picture and they are introducing a lot of models that are probably more about democratic management styles within supported accommodation and other places. (...) What we find is that the ones we deal with are pretty, the quality of them is poor. And it is a failure in terms of the structure for the staff, it is not fair for staff. It is unsupportive for staff, but it is dressed up in another way to make it look like it is an empowering model.*

Involvement of person - Advocacy

All parents were strong advocates on behalf of their children and participants felt that it was the advocacy work of parents that often resulted in positive outcomes. A number of participants used the term '*those who shout the loudest*' within interviews. These references seemed to allude to concerns that people with severe ID often rely on family members to get their voice heard, but that not all families might be able to be strong advocates.

Luke's mother: *There are other young people, who maybe don't have somebody (...) strong enough to challenge people. And what about them, what about those kids?*

Family support service: *The only people who have a voice on their behalf are their family carers and if family carers speak out quite often they are told you are a family carer, it is not about you, it is about the service user, but my daughter or son can't speak and I am them, so it is very difficult.*

Parents' reasons to pursue supported accommodation highlighted the interdependence of their own lives and that of their children. All parents stressed that they were aware of their own aging and had wanted to avoid a crisis situation in the future.

Ben's mother: *If there is anything happening to either of us, or both of us at the one time, it would be horrendous for Ben. He would be ripped away from his house, he would never see his parents again and also (I) wanted us to be around to still be there to reassure him and also to iron out any problems.*

Next to parents, adult services seemed able to take on advocacy roles in Luke and Ben's case. In Luke's case his adult day service had argued successfully for the importance for him to be able to continue at the service after his move into his accommodation. Similarly, Ben's adult service had negotiated with social work to get extra funding for an extension and more night support for him. However, in Lisa's case both of her day services had little involvement in the early stages of finding supported accommodation.

6.3.2.5 MACROSYSTEM

This theme will discuss how policies and available resources shaped the transitions, as well as discussing views on inclusion.

Politics and economy

Participants referred to concepts such as choice, person-centeredness, independence and inclusion as underlying practice. Yet, at the same time, there was an acknowledgment across cases of a decrease of resources since austerity. A couple of participants (team leader of the family support service, team leader in Luke's day service) discussed the introduction of Self-Directed-Support (SDS) to illustrate that in their view, choice was linked to what was available instead of what families ideally wanted.

Family support service: *When they started to talk about choice, choice and control, which was the strap line for self-directed-support, it was not really choice and control. Your choice was, would your son like to be in his adult day centre five days a week or would you like four days and his respite. You had to then choose which bit to give up.*

Participants in Lisa and Ben's case described paucity of housing as a main barrier for families currently looking for supported accommodation. Additionally, across cases, participants referred to recruitment problems within the social care sector. The rise of the minimum wage was given as a possible reason for recruitment problems, as it had resulted in other jobs offering people similar pay with less responsibility (e.g. working in supermarkets). There was a sense that while policies and quality criteria were becoming more demanding, resources were decreasing. There was an acknowledgment across cases and participants of the complexity to meet policy ideals within a system that had been under stress for some time.

LA manager: *We need to try and get the maximum benefit from an increasingly smaller pot of money. Seventy million pounds have been taken from [our] council in the last eight years. If somebody can tell me that there is not a reduction in quality then I'd love to see their analysis. (...) I believe that people with a learning disability deserve a high level of care. They are some of the most vulnerable people in society and any society is measured by how it looks after the most vulnerable people in it. And if we don't do that properly then we have done something radically wrong. And it cannot continue to be about money, it is a moral issue as well.*

Culture

Almost all participants (except LA Manager and two professionals of Luke's day service) discussed that after the transition into supported accommodation, most people were expected to be supported by only one service. Parents and professionals felt that this often resulted in people having fewer supportive environments in their lives. All mothers talked about the difficulty of finding suitable local places where their children were accepted as they were. Parents in all cases paid for their children to access additional services and there seemed to be questions around who should fund activities such as art or music classes. This touched on questions such as 'How do we share resources with everyone?', 'Who has priority?' and 'What is a good life?'

Luke's social worker: *I found it very difficult it was a bit like trying to grab jelly. I didn't know what I was going to be able to offer and what was reasonable.*

6.3.2.6 CHRONOSYSTEM

Reflections on what comprised a good life for people with severe ID were closely linked to views on the past and present service provision context. In all cases questions were asked about who would care and feel responsible for the person once parents were not there anymore and if services could offer a place of belonging to the person with severe ID.

Future responsibility – Who will care?

Participants shared their views on what adult service provision should or could look like and here many parents and professionals reflected back on the past. Parents and professionals still remembered the time when adults with severe ID were looked after in institutional care. Everyone agreed that this had been a dark and all too recent chapter in the history of intellectual disabilities. Not wanting to be associated with memories of past institutions seemed to influence how participants talked about current service provision. For example, shared accommodation (including homes for two or three people), group settings and being supported within the same environment for many years seemed to have negative connotations for some.

Luke's day service 1: *I am a bit worried about, we are a transition project (...) there is a bit of a concern that we could become seen as an institution if nobody leaves and nobody moves on and transitions to something else.*

At the same time a number of participants (adult service providers, the family support service, Luke's mother, Lisa's brother, Ben's parents and the local authority manager) voiced concerns about single tenancies within a climate of funding cuts.

LA manager: *People can be living in a house themselves in the community in a flat, but they can be more institutionalised and lonely than they could be living in a hospital setting with hundreds and hundreds of people.*

In Lisa's case her brother had committed to a guardianship role, while in Luke and Ben's case parents were concerned who would take on guardianship in the future. Luke and Ben's parents felt that social work would be unable to take on the role as they had little direct involvement in the lives of their children and because social workers often changed.

Luke's mother: *I would not want Luke to have them as guardians, actually because not the way it is at the moment.*

In Luke and Ben's case there was evidence that parents felt that their children's current adult social care services were not only able to meet their children's basic care needs, but that they were able to advocate on their behalf and support their development. It seemed that consistent relationships with staff helped parents to feel able to trust that services could offer their children a place of belonging outside the family. Similarly, Lisa's mother discussed how she wanted Lisa to be looked after by a service, instead of employing staff herself, as she felt that services were able to offer greater consistency and could take on some of the responsibilities of managing Lisa's care in the future. Yet, while Ben's parents were very positive about the role of the adult service in his life, Luke's case illustrated a higher complexity. Although his mother felt that his day service knew Luke well and was a great support in his life, she voiced concerns that both his services were still organisations that were dependent on funding and recruitment. Thus, she felt that there was always an uncertainty about the services' ability to look after Luke, which increased her anxieties about the future. Similarly, the team leader of the family support service in Lisa and Ben's case talked about a recent experience of supporting a different family. She used the example to reflect that some families felt that staff were often unable to replace the bond shared between family members and people with severe ID.

Family support service: *They have been very disheartened by how it has been. I don't think there is anything, nothing wrong with any of the staff, nothing you can put a finger on, but the mum feels they just don't engage their son enough to give him the best quality of life he needs. (...) Of course, there is a worst-case-scenario, he could choke or not being monitored during a seizure or will he fall out of bed, but those are the things that agencies usually don't allow to happen. It is the other bits and that is hard.*

Interestingly, although Ben was the oldest of the three, his parents seemed to worry least about the future. Ben had been supported by his service for over fifteen years, with key staff members still involved. His service described how they had experience in supporting others towards the end of life and that this usually involved working closely with specialised services, such as palliative care teams. His parents seemed to trust the service and the service appeared

committed, while admitting that towards the end it was sometimes necessary for people to move into more specialised services.

6.3.2.7 Concluding remarks

Using Bronfenbrenner's model helped to highlight gaps between ideal-led policies and practice at times of decreasing resources, particularly in relation to SDS legislation, social inclusion and community participation. Parents in this project did not see benefits of getting direct SDS payments and managing the care of their children themselves. Reasons given by parents related to the complexity of managing staff and paperwork, that it could leave them in the difficult position of being caught between services and social work in instances of price increases (Luke's case) and that, in light of their own aging, parents wanted professionals to take on more responsibilities

Different environments and networks where social interaction was taking place were identified. Those included the person's supported living or day services, family, college (Luke), vocational work (Ben), peers and hobby groups. Parents continued to facilitate and pay for activities for their adult children (including therapies and hobby groups) and both social care staff and parents spoke about difficulties to find possibilities for social inclusion and learning environments within local mainstream settings. The importance of staff to facilitate 'good lives' was highlighted, and participants criticised that although support workers are faced with high responsibility, their pay and training is relatively poor.

Overall, findings in this study show that needs and likes of people change throughout adulthood, which requires an ongoing involvement of professionals. However, within adult social work, social workers only got involved to respond to concrete situations, reflecting an experience of discontinuity for families. Key-professionals within the services that directly support the person with severe ID had a longer standing involvement and were better placed to offer consistency and take on advocacy roles. While all cases highlighted the complexity of facilitating involvement and engagement, social care professionals and families illustrated how they made decisions about activities and routines based on close

observations of Ben, Lisa and Luke's behaviour, and all three adults were seen as able to communicate their likes and wishes.

6.4 Summary of main findings and links to existing research – a 'small' discussion of study one and study two

Findings across study one and two highlight concerns about transitions that have been identified by others, specifically, lack of early planning and information for parents (Cox, 2017, Hardy et al., 2005), tensions between an understanding of the transition as an event from one service to another within the organisational context and families asking for a whole life-course understanding (Cox, 2017, Jindal-Snape, 2016) and a widening gap between ideal-led policies and resource-led practice at times of austerity (Lenehan, 2017, Mansell and Beadle - Brown, 2004, Roulstone and Morgan, 2009). Both my studies were able to add to existing findings through a focus on multiple perspectives and processes within an ecological model. Through the use of timelines, I was able to identify critical developments, circumstances and periods in people's lives that either required local authorities to become involved, that started transition processes or led to changes in decision-making processes (Ledger, 2012). Those mirror ecological levels and can be summarised as:

- **Changes within the needs or behaviour of the person with severe ID.** Observable in for example the occurrence of incidents or review of medication (Luke, Tom, Ben, Emma's case).
- **Changes within the family system.** Parents becoming more aware of their own aging and ability to look after their children in the future, wanting to avoid a crisis situation (all cases).
- **Practices and set-ups of adult service providers.** Namely, services having age-limits, requiring the person to move on to a new service as they are getting older (Peter, Luke and Ben's case), as well as the ability of providers to meet the needs of the person in relation to their physical spaces, staff levels and experiences and training of staff (Ben, Luke's case).

- **Local authority practices and available resources.** Namely, changes in the allocation and availability of social workers (Predominantly in Luke and Lisa's case, but experienced by families in all cases), as well as limited spaces within services, lack of available and suitable housing, services running at capacity and reduction in funding available to families.

Using an ecological model helped me to make a distinction between 'practical transitions' (Mesosystem) and 'organisational transitions' (Exosystem). Findings showed that the involvement of people with severe ID differs between practical and organisational processes, between their Micro- and Mesosystems and Exo- and Macrosystems, as has been suggested within the literature on healthcare transitions (NICE, 2016, Care Quality Commission, 2014). Although not specifically referring to people with severe ID, guidelines around healthcare transitions make a differentiation between transfer and transition. The transition is defined as the whole process involving early planning and later support while transfer refers to the actual move (NICE, 2016, Care Quality Commission, 2014). By drawing on the perspectives of different stakeholders, my findings highlighted differences in conceptualisations of participation. At times participants connected participation to the ability to be independent and rational. Such conceptualisations doubted people's capacity to be involved in decisions. This was contrasted with a more relational understanding of participation and involvement that emphasised advocacy and valued consistent and supportive relationships in people's lives. Within practical transitions there was a stronger emphasis on the involvement of the person. People communicated their needs and likes or dislikes through their behaviour, for example by refusing to do an activity, by showing signs of distress or by showing their enjoyment through laughing, smiling and increased levels of interaction. Those who knew the person well, were able to interpret their behaviour and understand their unique way of communicating. Thus, there was a clear indication that people had agency within their immediate environments and were 'listened to' (Kruithof et al., 2020). People's needs and behaviour within their immediate environments influenced decisions that were made to some extent. At the same time both studies highlighted familiar complexities in interpreting people's behaviours and tensions between 'choice' and 'best-interest' (Dunn et al., 2010, Ferguson et al., 2011).

Additionally, the complexity of how to interpret and respond to behaviour that was deemed 'challenging' was discussed, such as refusal or aggression, and how to widen people's experiences of different settings.

My data showed that if people are attuned and receptive to the person's communication, they are able to take on advocacy roles. However, translating people's preferences and actions into views requires a level of interpretation. A collective approach seemed to help those that knew the person well to collectively negotiate their views and preferences and to facilitate their involvement within the practical move. This mirrors the work of others who stress the importance of collaborative practice when facilitating participation of people with severe ID (Grove et al., 1999, Simmons and Watson, 2014). Yet, it also highlights the vulnerability of people who do not have closely involved families as advocates. Mirroring other research the two studies show that the family often remains the individuals' main and only social network outside of professional systems (Kamstra et al., 2015, Wilder, 2008), but my findings also suggest that professional networks and spaces can offer a sense of belonging, opportunities for social interaction and that professionals and people can form close relationships (Hall, 2010, Power, 2013). In all cases there was evidence of close relationships between individual professionals, people and families. However, there was also a clear sense that the involvement of professionals was not always reliable. Some relationships ended once people moved from one setting to another and even within settings relationships discontinued, reflecting issues of staff turnover in both social care and social work (Moriarty et al., 2018). At the same time in some cases individual professionals had been part of the person's life for many years, showing commitment of individual professionals to stay involved in people's and their families' lives. Similar to Small et al. (2013) my data showed that the role of friendships and peers was scarcely considered when making decisions about people's transitions and only Ben, Luke and Lisa's mother and team leaders in Luke and Ben's cases talked about trying to support continuity of friendships.

Overall, the central role of mothers in advocating for their children and caring for and about them stood out. Research has long highlighted the central role mothers play in the lives of their disabled children (Kittay, 2001, Kruithof et al., 2020, Rogers, 2016), showing how mothers and their children's lives are closely

intertwined and needs are interdependent. In all cases it was mothers who had limited their work to support their children. This involved looking for rehabilitation possibilities, therapeutic and educational programs and implementing them, advocating on behalf of their children and getting involved with charities and advocacy groups and the wider learning disability community on a local level. Yet, similarly to other studies my interviews with two fathers and one brother also highlighted close connections and showed that fathers and siblings played important roles in the lives of the person with disabilities (Boström and Broberg, 2014, Davys et al., 2015, Davys et al., 2017, Jacobs and MacMahon, 2016). Themes and worries expressed by the two fathers and brother were similar to that of mothers and highlighted a similar amount of emotional stress.

Taking an ecological perspective and exploring wider levels, alongside people's immediate environment, illustrated the role of cultural, economic and political spheres. Not only named stakeholders played a role, but 'the system' emerged as an actor. This seemed to be a dubious actor, referred to as 'government', 'budgets', 'higher up', 'corporate world' or 'money'. Similarly, Altermark (2016) describes that 'the opponents' disabled people are faced with might not be actors or groups, but systems and ideologies. The role of wider systems, ideologies and organisational practices will be explored in more depth within the main discussion chapter.

6.5 Study three: Transitions in old age

The approach in study three differed from the previous two studies in its design, with a focus on exploring the views of social care professionals in two distinct social care settings. The aim of the study was twofold: (1) to explore old age as a life stage, particularly changes in needs and circumstances that were identified by participants, and (2) to explore what informed the practices of social care professionals in supporting people in old age. Seedhouse's ethical grid (2009) was used to explore what informed participant's practice through an ecological lens.

Adult services can look very different and due to the specific nature of the two services, study three did not aim to generalise across adult service delivery, but to start an initial exploration of the needs of aging adults with complex needs. Participants asked to refer to adults with intellectual disabilities as people they support and the term people will be used throughout findings and at times people who receive support will be used to clarify content. The settings will be referred to as communities.

6.5.1 Two communities and the transition journeys of three men

Both communities were very similar in their set-up, comprising of several houses where people with ID and staff live together, either in the same house or neighbouring houses. The first setting was slightly smaller and set in a rural area of Scotland, while the second one was bigger and part of a city local authority. Both communities had cafés and shops that were visited by the public and which sold craft and food that was made by people within the communities. People worked in the café, shop and workshops in close proximity to their houses.

During interviews a number of references were made to the cases of three men who had passed away in recent years. A short summary of each case will be given below. The summaries are closely aligned to passages from interviews and direct quotes from interviews were used when possible to describe the three transitions journeys from the perspective of participants involved in their support. Direct quotes are in italics.

6.5.1.1 Transition profiles of Gary, Martin and Steven

The three narrative profiles that were crafted can be seen in the table below.

Table 37: Three transition journeys in old age

GARY

Gary lived in the community for over thirty years. He had a diagnosis of down-syndrome. He did have some speech and liked to repeat certain phrases. He was able to say 'yes' and 'no', and you could have small conversations with him. *He did not have complex comprehension and also wouldn't have been able to understand a complex question or even a simple one necessarily and reliably give an answer that was meaningful* but he was able to communicate through showing his feelings and through his behaviour.

He always had his own routines and it took him a long time to get ready but when he got *older he took longer and longer. That shrunk what he was able to do in his day because he spent so much time getting ready to go. You felt gradually 'oh I don't think there is quite the same connection', a gradual feeling of his comprehension becoming more limited and belonging to the here and now.* Often he did not want to participate in social activities anymore.

Additionally, over quite a number of years *he would put things in funny places.* In his fifties he was diagnosed with dementia. Getting lost and wandering around became a big worry but specialist equipment such as bed sensorshelped with that.

Gary's parents had passed away a long time ago and his brother lived in England. Gary used to visit him and at the end of his life his brother came to visit him in the community.

There was never any guardianship agreement in place and that was difficult for the community. People had to trust when *his local authority said 'oh it will work out'*. He managed to stay in the community until the end and he died in his room with other people there holding his hand.

MARTIN

Martin had only very limited and very hard to understand speech and as he got older and more confused that got less. What became a very clear way of expressing was he would cry and he got very distressed when left alone.

Doing things by himself used to be very important for Martin and that changed quite dramatically over a short period of time, from being rather independent to us then realising that if we don't prompt him with getting dressed, he would not get dressed, to very quickly to help him to get dressed and the same happened then with eating.

He had down-syndrome and was diagnosed with dementia between two to three years before he died, but already around eight years before his death he took a slower pace.

A couple of months before he died he moved to a local nursing home. The community felt unable to provide end of life care and once a vacancy came up locally it was decided by all professionals that it would be best for him to move there. His local authority had taken on guardianship to be able to make the decision, a process that took a long time and was only finalised close to the move. His parents had both passed away and his siblings lived far away. His social work team was very good, they would come every three months for the last couple of years of his life.

There were two options, either choosing a specialist home in a different locality or a local nursing home. As he did not have any family close by everyone agreed that although he wasn't local to the area that he should stay there so that people in the community could keep in touch with him. Whether that was the right choice is the question, but you don't always have that choice cause it depends on vacancies. That was heart breaking for us to come to that decision but the decision was taken by all these people involved.

He died six weeks after moving to the nursing home in hospital. A number of people from the community were with him when he died. His brother had visited shortly before.

STEVEN

Steven had very limited speech. He had a few words which were sort of used to cover everything, car being one of them, but it was hard to know. He always had had mobility issues. Steven was diagnosed with a brain tumour when he was in his early fifties and early on hospice and hospital staff were closely involved. His parents were very closely involved and would come up and see him and the community would be in touch with them and keep them in touch with how things were going. He continued to live in the community and then had times where he stayed in the hospice or hospital but people from the community continued to visit.

In the end he died in hospital and people from the community were with him till the end.

6.5.2 Synthesis of findings utilising Seedhouse's ethical grid

The following section will draw on interviews and group discussions with social care professionals in both communities. Seedhouse's ethical grid was used to synthesise findings and explore how social care professionals made decisions and how they involved people within transitions in old age. Seedhouse's grid consists of four layers to explore what influence people's actions, drawing on deontological and consequential theories to understand ethical decision-making, as well as seeing the person (at the centre within the core rationale) embedded within wider environments (external layer) (see table 26). The grid was able to highlight the ethical realm of the work participants were involved in and I was able to highlight influences across ecological levels.

Table 26: Layers of Seedhouse's ethical grid

Core	The individual and his or her needs and rights are at the centre
Deontological	Is concerned with the way in which things are done and the duties and obligations professionals experience.
Consequential	Encourages to think about the consequences of possible actions for others.
External	Includes external influences across Macro, Exo and Mesosystems including laws, codes of practice, available resources as well as collaborative practice with families and other professionals.

Different decision-making processes were discussed by participants in relation to transitions in old age. Those included changes in everyday practices as people's need increased, such as supporting people's personal hygiene and food choices, as well as decisions around medical treatment. Bigger decisions that were discussed included the need to implement changes to people's programs and routines, transitions into nursing or palliative care homes, as well as end-of life care. Participants referred to their experiences of supporting people across the spectrum of mild to severe intellectual disabilities. All data was included in the analysis but instances where participants explicitly referred to people with severe intellectual disabilities or severe communication difficulties, including people who had developed dementia, are highlighted.

Based on the data a number of changes were made to Seedhouses's grid (see figure 15 and 16). First and foremost, participants in study three had a more relational understanding of their work and therefore the core layer reflects themes

that emphasise the relational nature of decision-making, including themes of identity, equality and involvement, instead of focussing on autonomy as the guiding principle of the core layer. Knowing about people's needs and wishes depended to a large degree on the interpretation of participants and participants' conceptualisations, observations and responses to people were highlighted in the core layer. The consequential layer combined benefits for the individual and professionals to emphasise how participants spoke about consequences for people and themselves as interdependent. In the deontological level two values were included that are not part of Seedhouse's ethical grid, but which were widely referred to by participants. The theme 'Keeping promises' that is included in Seedhouse's grid was renamed 'Respecting people's feelings of belonging'. It addresses similar concerns but was renamed to address the specific focus participants spoke about. Additionally, the values of mutuality and reciprocity were added. The external layer included less themes and focuses on specific external influences that were discussed by participants.

Figure 15: Seedhouse's ethical grid (2009, p. 164)

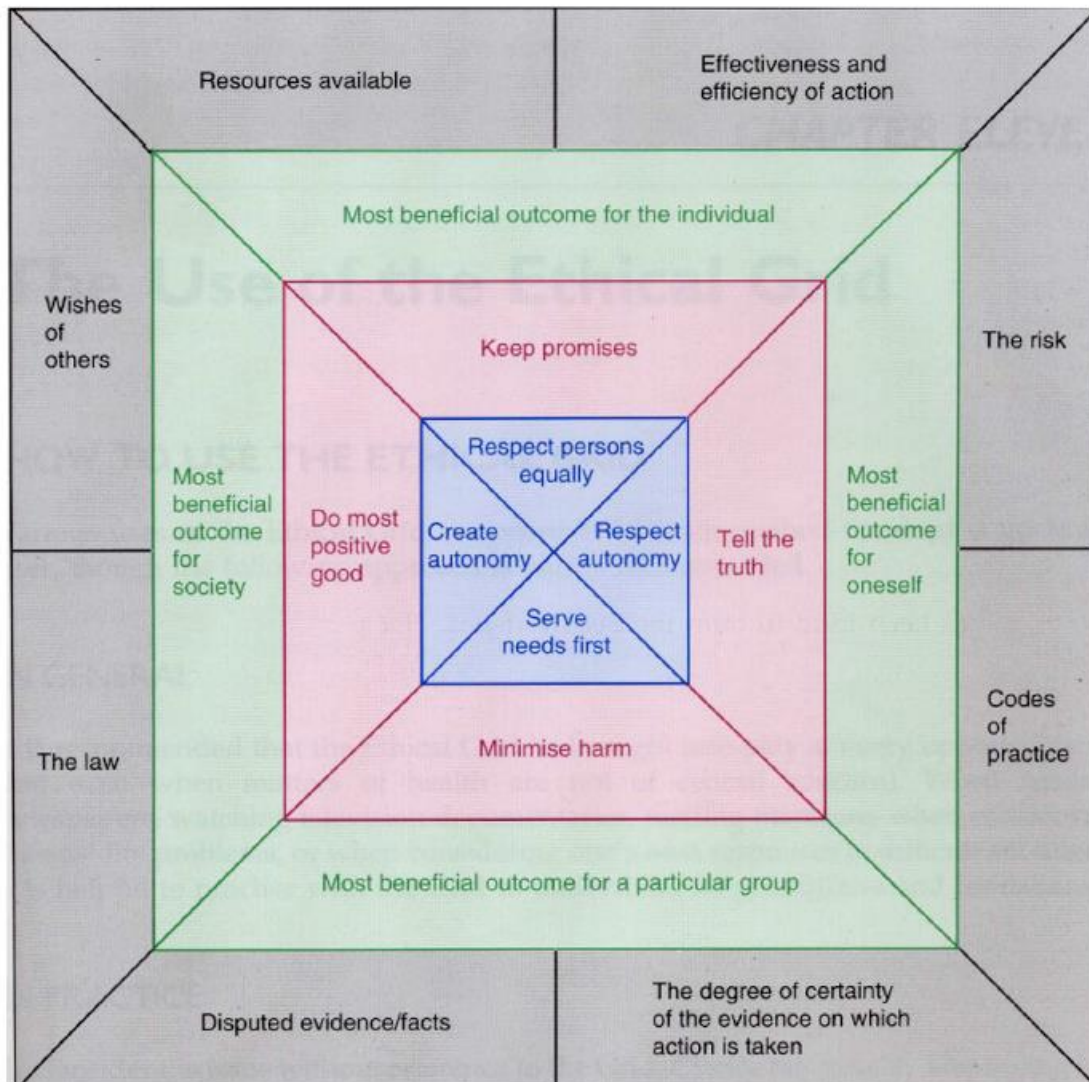
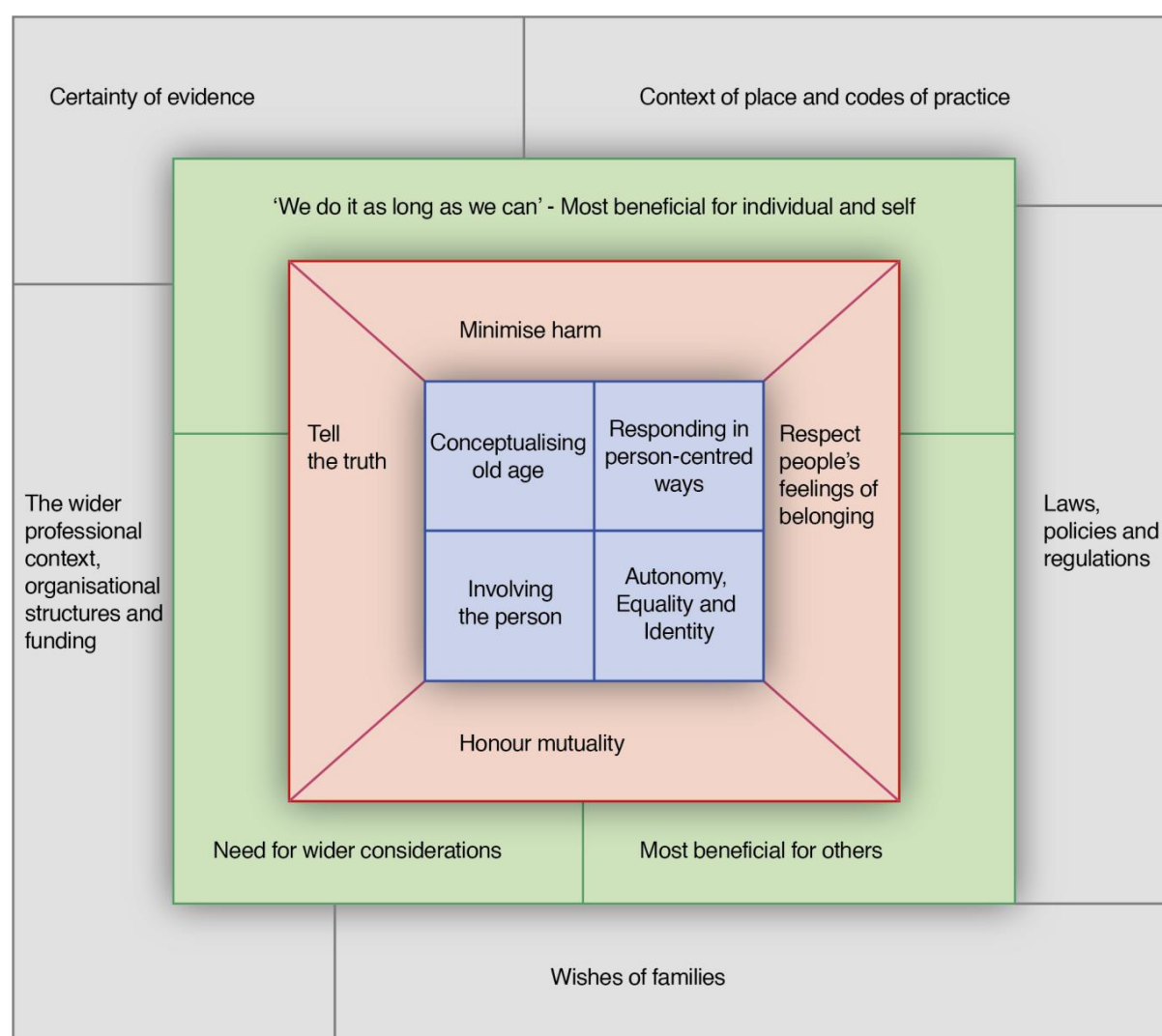


Figure 16: Revised grid - A-posteriori framework



6.5.2.1 THE RELATIONAL LEVEL – YOU AND I

How people conceptualised old age helped to clarify in which contexts decisions needed to be made and how professionals described the needs of people changing. Subsequent themes had a greater focus on actions and describe how participants identified changing needs and responded to them, in how far people were involved in decisions made and in how far core values (autonomy, equality) were practiced.

Conceptualisations of old age

Participants described that transitions into old age were very individual. However, aging was described as happening earlier on. Most participants spoke of a

gradual slowing down process with people needing longer for tasks, being more tired or preferring more time by themselves.

BETH: *Often it starts with people just needing longer for everything. Not managing to do what they used to do in the same pace (...) and making choices not to be part of everything.*

Overall participants identified many similarities between the aging processes of people with and without intellectual disabilities. Similarities were identified in relation to physical decline, but participants described that people's understanding of those changes often needed a different kind of support. One participant reflected that some people seemed better able to accept an increase in support needs than people without intellectual disabilities, maybe because their lives had always included an element of dependency. Others felt that it could be a more difficult process for people. As people had always depended on the 'care system' their choices had always been limited and the transition into old age often involved a further decrease of choices and possibilities.

JOAN: *Maybe the way old age limits anybody's choices has more of an impact on them but I think that is something that happens with anybody, sort of life closing down and becoming more limited in scope. It is accentuated by the fact that for many people their scope hasn't been as much as you would want it to be anyway.*

Participants reflected that noticing a decrease in abilities could be difficult when people had always required the support of others to varying degrees and that communication difficulties further complicated an identification of the transition into old age. For example, participants described that it could be difficult to know if a reluctance to do a task or join activities was connected to people feeling bored and wanting a change, if medication or other underlying health conditions such as epilepsy were the cause of behaviour or if it was due to people aging. Additionally, as people's medical needs were increasing, resulting in the need for more appointments and medical interventions it could be difficult for participants to judge where people with limited verbal communication felt pain. The tools, values and resources participants drew on to support people and make decisions will be explored in more depth in the following themes.

Dementia stood out in all interviews as involving unique challenges. Often dementia seemed to develop earlier in life, particularly in people with down

syndrome, and it could be difficult to diagnose early onset. The later stages of dementia were discussed as being no different to dementia in people without intellectual disabilities.

HELEN: *When it is things like dementia I think then you really can't see a big difference anymore. Is this now a person who was a professor and has now Alzheimer or is this a person with a learning disability with Alzheimer.*

Observing and responding in a person-centred way

Participants described the importance of being aware of small changes in routines and behaviour to be able to identify needs and respond in person-centred ways. It seemed to be easier to notice changes in physical abilities, such as finer movements getting lost and to respond to them. Recognising and responding to changes in people's cognitive abilities and emotional needs as a result of their aging was described as more difficult. Here participants reflected on the importance of spending time with the people they support and knowing them well. This was discussed from a perspective that included both participants knowing the person well, but also people knowing participants well and feeling safe around staff.

SOFIE: *I have lived with the people I support for a very long time, some of them for nearly twenty-three years. They know me and I know them.*

Knowing people well helped participants to respond in person-centred ways to address the need to change routines or put more support into place. For example, some people were described as responding better to verbal, others to written or picture-based communication when for example, discussing changes in routines or medical examinations. The importance of continuity and close relationships was highlighted in cases of people with severe intellectual disabilities and those with little verbal communication as well as those with dementia. Close relationships seemed to allow participants to relate to and communicate with people on a different level. This 'level' was referred to as intuitive, situational, non-verbal, common-sense or trust-based. Behaviour was described as the main means of expression for people and therefore working with atmosphere and being attuned to each other's body language seemed to be a tool that participants could use to understand and communicate with people.

A further example of the relational and situational component of decision-making was present in Mia's description of supporting one man through the end of life and making decisions about withdrawing treatment. The decisions to stop medical interventions seemed to be born out of a relational understanding of his changing needs.

MIA: *There just seemed to be a very clear point when everything was, I think Gary himself was getting tired and it was funny how clear that was, just this point of 'ok now we just really need to make Gary comfortable and do everything that we can', rather than fighting to have more and more time. To just really make the time we have got really good. So I think in terms of resuscitation and withdrawing treatment it would have been very hard to make those decisions any earlier than we did.*

Later on Mia reflected that the decision to withdraw treatment was made in close communication with his GP and she stressed the importance of collaborative practice to support her own assessment of situations. Additionally, participants described the importance of seeing behaviour as communication and listening to people's behaviour. Some participants described how this could be difficult in crisis situations and in the presence of challenging behaviour but that it was important to see all behaviour as communication.

JACOB: *I see it as my responsibility to maintain an openness towards their experience and how their wish might be to have fundamental changes in their lives but they might not be able to express this and behaviour can be a way of expressing, challenging behaviour, self-harming behaviour can be a way of expressing the dissatisfaction.*

Concerns were raised around transitions out of both settings into nursing care services, where people would not have established relationships to staff. This was one of the major dilemmas identified by participants: Seeing great value in long lasting and consistent relationships, while at times coming to a point where they felt that people's needs could not be met in the communities any longer. This aspect will be explored further in other themes especially the deontological layer.

Involving the person

All participants showed an awareness of their own influence on decisions made and the power imbalance between themselves and people they support. Participants emphasised trying to involve people in daily decision-making but also felt that they had a responsibility to guide bigger decisions around medical care

and to some extent also smaller everyday decisions around food-choices or suitable activities. Participants described a need to constantly reflect on their own role within decisions made or choices offered by speaking to colleagues and healthcare professionals, closely observing people's behaviour and putting themselves in their position.

JACOB: *There might come a time of having to familiarise yourself with what is the experience of that person really like. Because it might be different from mine or different from those of my colleagues but usually when it comes to advocating for the person I think that is my responsibility.*

Responding to and interpreting people's behaviour in the 'right' way seemed to be complex and many participants spoke about the fine line between accepting that people's behaviour illustrated a choice and encouraging engagement and healthy living.

JOAN: *You might be weighing up what is sort of feeling too much for him but also the huge danger of him just literally lying about and just getting bigger and bigger and more and more unhealthy so it is the movement isn't it? Sometimes it is the sheer movement that one is trying to sort of keep hold of.*

Participants described that it could be difficult to involve people in decisions about changes in their activities (for example encouraging activities that require less physical activity) as some people might be very compliant or others would say no to most new activities. Continuing to offer people opportunities in situations as they were occurring and then observing their responses seemed to be a helpful way to promote an involvement that was situational and did not only rely on verbal comprehension.

MIA: *It is trying something out and then seeing, seeing then how people respond and how happy they are with the change.*

Supporting people through the process of losing areas of independence was described as requiring time and sensitivity. A number of participants described examples where people themselves became more aware and accepting of the need for changes as they experienced their own limitations.

JACOB: *[With one lady] we had a few days, maybe a week where she took half an hour to walk up the stairs. I think that there it really sank in for her that something was going to change.*

Collaborative practice was stressed as key, especially in cases of people with severe intellectual disabilities, dementia and at the end of life. Decisions that

involved a change in care setting or substantial changes to people's support packages were made in reviews together with health and social work professionals and if possible relatives. If possible people were part of those meetings but a number of participants reflected that often people's ability to be involved was limited at this stage, as meetings often took place once a crisis had developed and the person had deteriorated.

OLIVER: *Often we are at a point where the individual probably would struggle to and that is not only down to communication issues but also with the reality of the pace of the system and how it works.*

Being proactive was described as best-practice to avoid crises situations. In cases of people with mild or moderate intellectual disabilities participants described that they tried to involve them when they were still well in conversations around how they would like to be supported in old age.

OLIVER: *Because you have a learning disability does not mean you have no choice and that is why I said there is a side of it which, and I think probably in every area of social care, to have those conversations before it is in inverted commas too late.*

Autonomy, Equality and Identity

While respecting and creating people's autonomy was described as an integral part of participants' work, promoting autonomy during the transition into old age, where people were becoming more dependent, seemed to be challenging. Participants described tensions between respecting people's autonomy and their duty of care.

BETH: *That was quite a big step then to realise that we actually have to hold the fork and feed him and we were always resisting taking that step because it is obviously taking someone's independence completely but it was necessary otherwise he wouldn't have eaten anything.*

However, even though support needs of people were increasing, promoting autonomy was still featured in interviews. For example, participants described efforts not to focus on people's limitations but to rather adapt people's environments to minimise risks and facilitate engagement.

SOFIE: *You put rails in the bathrooms, you put anti slip mats.*

It seemed that autonomy was conceptualised by participants mostly in relation to meaningful engagement and access to activities and tasks rather than to doing

things alone. In this way autonomy could be achieved through the support of others.

ROSIE: *We have an activity we do together and so I can enable them to feel good about themselves and that they have something valuable to give.*

Older age and becoming more dependent also marked a change in people's identity. People seemed to need support to make a step into a different life phase, one that seemed to be less closely defined for people with intellectual disabilities.

SOFIE: *I think that is maybe where the learning disability comes in. So called normal people retire, it is a natural process, whereas here people don't retire in that way.*

Participants described that many people strongly identified with their work and workshop settings. The loss of, for instance, working on the farm could be difficult for people and participants described the importance of involving people in finding new meaningful activities. Respecting people's identities was a strong theme across interviews and included an awareness of their life histories. Valuing people's past lives by creating photo albums or memory boxes and remembering their passions and interests at funerals were striking examples of how both settings attempted to uphold people's life histories.

ROSIE: *I contacted the families and with their permission we wrote letters and where there was no families, social workers. So for each of them I made a book and that was a most precious thing for them. Some of them when they passed away the families took the books along and I wrote things with them. Even with the ones who had no language I would say mum, dad and a smile.*

JOAN: *There is a double decker red bus that you can hire in the area and we hired it for two funerals (...) because both people absolutely loved buses and so the whole community went to the funeral in the red bus.*

6.5.2.2 THE DEONTOLOGICAL LEVEL

This layer describes the duties and obligations people referred to. Risks were discussed by participants in the context of their obligation to minimise harm and therefore risks were moved from the external level to be discussed in the deontological level. To minimise harm and risks seemed to stand at times in tension with the other duties and values participants spoke about, namely to respect people's feelings of belonging to both settings as their homes and the value of mutuality.

Minimise harm and risks

When participants spoke about their duty of care and responsibilities, minimising harm and risks were often referred to as reasons for making decisions, particularly people moving to a nursing setting. Risks to people themselves and others were referred to in the context of dementia and absconding, aggressions, rejection of medicine, food or drink and an increase in physical needs that required specialist medical care such as the development of systemic infections or pressure sores.

OLIVER: *The majority of times it [move to different setting] is due to additional physical care needs. They are so high that they cannot be provided from a housing support service basically and the other one is when it is around confusion, absconding.*

Respect people's feelings of belonging

This was one of the richest themes referred to by all participants. All participants described how it was important to honour that both communities were not merely care settings but people's homes. There seemed to be tensions between 'minimising harm' and honouring people's sense of belonging when it came to decisions around moves to nursing or palliative care homes. Participants spoke about a feeling of guilt and how it was emotionally challenging to make those decisions.

BETH: *It is the kind of dilemma and decisions very similar to when a family supports someone, an elderly parent, and at some point you can't do it anymore. It is hard it is not easy.*

Jacob, similarly to others, reflected that in these instances close relationships could turn from a strength into a challenge as emotions of guilt became involved in the decision-making.

JACOB: *Relationships are our strength and in those situations relationships can also become our greatest challenges because I need to, as a carer, as a professional, to disconnect from my human connection to that person and not think what is in the best interest of us, but what is in the best interest of them.*

A decline in people's capacity, limited choices of nursing homes and funding constraints further complicated the process. There were differences in opinion if nursing homes were better able to address physical care needs and a number of

participants stressed that it was impossible to know where people would have been better looked after.

JOAN: *He got pneumonia in the care home which, I mean the amount of care that he had once he had gone there, although he went there because he needed more than we could manage here, was obviously he had in a sense much less (pause) personal care and one to one I don't think existed at all. It is just how it is, so we were very happy that we managed with Gary and enable him to be here right till the end.*

OLIVER: *There is a reason for people moving. (...) So in some ways yes it is better and in other ways it is not. I think it can often be a very lonely life to be in a nursing home.*

A number of participants suggested that it was at times down to one person feeling able to take on the responsibility and commitment to care for someone till the end of life. This seemed to be connected to the quality of relationship between individual staff members and the person, support available from colleagues and other professionals as well as the personal circumstances of the person.

ROSIE: *I think that is her dedication that he has found back his movement and his speech but not everybody can do that.*

All participants described that after people moved they tried to maintain relationships. This included regular visits to nursing homes, people coming back to the community for visits and participants maintaining an involvement with professionals and family members.

While some relationships could drift apart, there was a sense across interviews that in cases where people were more vulnerable, with little capacity to make themselves understood, to understand changes and where family involvement was limited or non-existent, both settings would strive to continue to be involved. Six interviews included portrayals of participants being with people during their last moments in life or organising their funerals.

HELEN: *We sat once more altogether around her bed and she was not even fully conscious anymore but we were just sharing memories just also for ourselves but hoping that she would hear it.*

ROSIE: *Some who have passed away they have come back here for the funeral. We do everything and they are here and they are never forgotten.*

Honour mutuality

Six participants discussed how a belief in mutuality influenced their practice. Mutuality was defined as the appreciation of the unique contribution each individual brings and to understand relationships as reciprocal, seeing both staff and residents as giving and receiving.

ROSIE: *I had the authority yes, but I don't know how to describe it, it is not words but we knew of each other and I was all the time learning.*

This seemed to help participants to conceptualise old age as a time in life where people continued to contribute despite an increase in support needs, even during their last weeks of life.

JOAN: *It was like a sort of anchor and other things would go on around him because he was there and it almost drew people to the sitting room. Because somebody was there so that was a lovely side of life and it was missed when they died by the other people in the house.*

While participants stressed the importance of being aware of boundaries and needing to adhere to professional codes of practice, participants seemed to feel that there was a more profound human quality to their work. Participants often used the word friend to explain how they felt about the people they supported.

MIA: *I mean it is something between friend and family I don't know. There is a closeness there that care just isn't the right word.*

JOAN: *It is more tricky if we are trying to think well who do I think what is my experience of what I am in relation to people who I have really shared my life with for the last 34 years or something.*

Tell the truth

Participants discussed that it was often difficult for people to engage with their own aging or that of their parents or other residents. In both settings it was stressed that death was not a taboo and that they tried to engage people in thinking about the end of life. Participants described that it helped people to visit those who had moved to nursing homes and to attend funerals. Particularly those with severe intellectual disabilities and limited verbal communication were described as benefitting from direct experiences.

BETH: *I think part of it is that they have been part of the process all the time. That they would have seen changes all the time and extra support that has been put in place and if someone did not feel well they would be all aware so you can gradually prepare people that it might come to an end.*

Additionally, two participants spoke about having photographs and items around to remember people and support others to remember them in everyday life.

In the second setting participants referred to regular groups that were run to give people the possibility to share experiences of loss, grief and death.

6.5.2.3 THE CONSEQUENTIAL LEVEL

Participants spoke about in how far their actions and decisions had consequences for the person and themselves. Their own needs and the needs of people were discussed as interdependent and therefore consequences for the person and for participants themselves could not be separated and they are combined in the first theme. Consequences for others and for society were only discussed briefly.

‘We do it as long as we can’ – Most beneficial for individual and self

Instead of speaking separately about how decisions were either based on what it would mean for the person or participants themselves, consequences were discussed in a relational manner that highlighted the interdependence of people’s needs and participants possibilities. This was most striking towards late stages of old age, dementia and end-of-life care, where people often needed to move to nursing homes, but also featured in smaller decisions around changes in routines and medical care. For example, deciding when someone would receive treatment was based on their sleep patterns as well as on the availability of staff. While participants stated that they tried to be flexible in responding to needs, they sometimes reached limits due to lack of staff and caring tasks becoming more time-consuming.

***OLIVER:** We do our utmost to make that possible [for people to stay] and we will do that up to the point where it is either not safe or in the best interest of the person. That is a constant tug of war between the emotional relationship and the practical, the pragmatic side of things.*

Most beneficial for others

The need to consider other residents was mentioned, albeit briefly and mostly in the context of aggression.

ROSIE: *We rather try and support within the community. Unless they turn aggressive and are a danger to others. Because for some the transition [into old age] is not easy and there is a lot of aggression, a lot of temper.*

Additionally, one participant discussed how it was important to involve family members if the implications of someone's behaviour could lead to a placement breakdown.

Need for wider considerations

Surprisingly the need to take into account consequences for society and a narrative of needing to share resources with others in need was missing from interviews. Participants expressed an awareness of the complexity of the wider service provision context and scarcity of resources but there was no evidence that it specifically informed their decision-making.

SOFIE: *I think it is a whole minefield this whole thing. I think it is difficult. It is working with people, with people's lives and elder care is not high on the list.*

6.5.2.4 THE EXTERNAL LEVEL

Resources available within both communities and its codes of practice seemed to be significant in shaping decision-making processes. Similarly, external resources such as funding, equipment, as well as laws, regulations and social work and healthcare procedures were widely discussed by all participants.

Context of place and codes of practice

In both settings participants and people lived together in the same house or neighbouring houses. Most participants had known the people they supported for many years. Participants felt that there was a lot of detailed knowledge of people and support from colleagues to support the transition into old age.

MIA: *People here just knew him so well and I think that makes it easier, even when his dementia was so advanced, to really make a connection. I think it is still hard to, hard to truly get somebody's views on certain decisions but I think it does make a huge difference. You are kind of surrounded by people who have very established relationships.*

Both settings only had a small number of employed staff and most did not work in a shift system, as they lived on site. Participants felt that it allowed them to be more flexible to meet the needs of individuals and respond to changes in people's routines

such as needing longer to get ready in the mornings or needing longer rests in the afternoons.

JOAN: *Another thing is that we're able to be very flexible about putting the support in at the moment that it is needed, because we are not relying on rotas and shifts where you suddenly haven't got anybody.*

The values that were discussed within the relational and deontological level, which seemed to reflect participants own principles, also formed part of the codes of practice in both settings.

JACOB: *There are guidelines for how to engage in those conversations [about the end of life] or it is part of our policies and procedures but we have got a pack from one of the local funeral homes to work on a funeral plan.*

Training for staff addressed care for the elderly and dementia. Participants in both settings talked about having regular meetings with colleagues to discuss individual cases or concerns and all participants received one to one supervision by colleagues. While support seemed to be available, in both group discussions participants discussed that their work could be emotionally demanding and that there was a danger for individuals to take on caring responsibilities without getting enough support from others. Participants reflected that supporting people with complex medical needs or people towards the end of their life requires the support from a group of professionals.

HELEN: *I think I did have the tendency to say that I can do it and then just plough through it also it was sometimes probably a bit much but it was also out of the commitment to my people.*

The physical set-up of the houses people lived in was described as a barrier and of increasing concern with an aging population.

BETH: *We realised we have very little rooms downstairs on the ground floor that are suitable for people who need an ensuite bathroom and all that. That is where a limitation is.*

All participants discussed that there was a lack of medical and nursing training for staff. This was more prominent in interviews in the second setting. Getting specialist equipment and the support from specialist nurses and healthcare professionals towards later stages in old age seemed to allow some people to stay.

Laws, policies and regulations

Participants referred to existing laws and regulations particularly around capacity assessments. There seemed to be a generational difference between families of

younger people having guardianship under the Scotland Incapacity Act or the Mental Capacity Act in England, while guardianship was not in place for most older people. Therefore staff were relying on S47 capacity assessment (Scotland Incapacity Act) done by medical professionals to make decisions about medical treatment. All participants spoke about working closely with GPs and other healthcare professionals to make decisions about treatments and interventions.

SOFIE: *We have these S47 in place where you can make decisions kind of on their behalf but I think that is a difficult thing to do because what is good for their health and wellbeing and where is an intervention actually too much and how do you judge that? I think that is where the GP can be very helpful.*

There were mixed experiences of cases where neither family members nor local authorities had taken on guardianship towards the end of people's lives. While some local authorities would take on guardianship to make decisions, other local authorities seemed to rely on collaborative reviews to make decisions in the absence of legal guardianship by anyone. Getting guardianship was described as a lengthy and expensive process.

BETH: *To get guardianship is an absolutely lengthy process and that is because the gentleman that we supported from the decision that the local authority should get the guardianship to the local authority actually getting the guardianship I think we are talking about one and a half years. So much about this man's destiny and where he ends up was connected to the local authority getting the guardianship.*

OLIVER: *[Local authorities] are meant to but they won't (laughs). Anyway local authorities and I think it is the welfare commission have contradictory advice on this matter and they both read the laws in different ways so legally they are meant [to take on guardianship] to but they are very reluctant to do so because it gives them responsibility. It seems to me from being a third-sector individual it seems to me they do not want that responsibility.*

Wishes of families

All participants spoke about the importance of involving families but stressed that in many cases of older people there was very little or no family involvement. Similarly, to the previous theme participants referred to generational differences and the historic context of institutionalisation. Many of the older people had grown up at a time where families were discouraged from being involved in the lives of their disabled children. Additionally, some of the older residents were not local and came from local authorities further away, which could complicate contact with families or social work.

OLIVER: *There is a small elephant in the room here with regards to (...) the cultural change that has been in regards to attitudes towards people with learning disabilities over the last thirty years. Many of the people we have in later life might not have a lot of relationships simply because they were cut off from family ties particularly in the 50s and 60s. You slowly see that there are stronger family relationships and I think it will change in the future.*

In cases where families were involved participants felt that family members trusted them to make decisions.

MIA: *I feel very much that they have a lot of trust in what we are saying and I feel a lot of responsibility there.*

Joan reflected that she felt parents' concerns about their own death was more present when their children would first move to the community. She felt that once people had lived in the setting for several years, parents seemed to be able to trust that the community would be able to take on responsibilities and support their children in older age.

JOAN: *By the time this is happening in their son or daughters life in a way so much of the son or daughter's life is invested in the community that they don't really have that fear. It is much more an issue when people are trying to find the right place for their son or daughter. (...) We'd have to be careful to try and say we can never say that this is a permanent place for ever because things might change. The person might change, they might actually not want to be here forever or they might for reasons of more volatility or for more nursing needs it might be that we can't manage. We would always be careful to say that because knowing that, that was very hard for parents to hear.*

In cases where there was family involvement parents had often passed away or were less able to be involved in the lives of their children. Towards old age siblings were described as taking on advocating and guardianship roles and becoming a main point of contact for staff.

BETH: *We see that in a lot of people's cases at the moment that it is almost like a parallel process because a lot of the people with learning disabilities do tend to age and at the same time their parents also get older and you kind of have these parallels. (...) You need to see if the siblings want to be involved. Luckily, in lots of cases siblings do take on an active role and one should not take that for granted.*

The wider professional context, organisational structures and funding

Both settings had established relationships to local GP practices, which was described as a big advantage. Particularly in cases of people with severe ID or limited verbal communication medical examinations were described as important to be able to

identify or rule out if changes in behaviour might be due to certain conditions or illnesses related to older age.

ROSIE: *It is always very important, especially for those who do not have verbal communication, that they get a thorough medical to rule out something. (...) Our people feel quite safe going to the medical practice because it is known.*

Experiences of working with social work were mixed. A number of participants remembered close relationships to social workers or specific local authorities and how this had been helpful to get extra funding agreed and to respond to the changing needs of people in old age.

BETH: *They were really good with giving us extra funding that we can employ people. They were really good in understanding our dilemmas and that we could not promise end of life care. The key is really the social work contact. If you don't have that back up you get very stuck.*

Others spoke about having little contact to social workers and finding it difficult to get hold of people to come and see the person, to attend review meetings and respond to requests for extra funding. Accessing health professionals seemed to be easier and participants spoke about receiving support from specialist cancer or palliative nurses who had come regularly to care for people within both settings. Specialist equipment could be helpful such as mattresses with sensors to alert staff but experiences of access to equipment were mixed.

SOFIE: *There is support aids, there is frames to get, there is hand rails to get, there is special beds you know all these sorts of things but in my experience I have to find them myself.*

Towards the end of life the support needs of people could increase within short time frames. In a number of cases participants had found the experience of negotiating extra funding as slow and difficult. In the first setting participants described how they had relied on support through the NHS to avoid crisis situations while waiting for funding from social care to come through to employ extra staff. At the same time recruiting social care staff to cover additional hours seemed to be complex with often limited interest. This seemed to be connected to funding being attached to only a few hours daily and living in a rural area.

MIA: *There was almost a bit of a, what is the word, a tennis match you know like who would provide the care for Gary. Social work said they were happy to fund it but there just were not the resources from the social care side and so that fell on the health professionals and we almost felt slightly in the middle because the nurses were lovely and caring but also sort of did remind us that it was more of a social care because Gary needed care rather than nursing. (...)*

There was no interest. All the local companies were either full or don't cover this area because we are so rural it is quite difficult. I imagine it happens a lot that healthcare services need to step in because of how difficult it was to find care through the social sector.

Decisions towards later stages in old age seemed to be influenced by the availability of placements in nursing homes. Most people were eligible for receiving funding for elder care through the Scottish benchmark system. Participants suggested that spaces in local nursing homes, especially at a benchmark level were scarce and Beth remembered that she felt that this had increased pressures to accept a place as it became available because it was unsure if a place would become available again in the future.

OLIVER: *I think the main challenge is to find appropriate care or any care at a benchmark model. There is not a lot of choice. The only ones who are in a situation of choice is where people have additional funds themselves.*

Participants felt that staffing was an issue in many nursing homes they had contact with and that there was little knowledge of learning disabilities and communication strategies.

OLIVER: *Medical care is getting better and better, people live longer but also live longer with personal support needs, and the major challenge around it is the recognition that somebody with a learning disability or additional support needs might need a different approach. (...) One of my frustrations around it is that it [staff training] would be fairly straight forward to implement.*

Certainty of evidence

The difficulty of knowing what people would want has been discussed within the relational level. While a commitment to involve and engage people was clearly visible across interviews, all interviews also included a feeling of never being able to fully know what the person would have wanted, nor knowing how much the person was able to understand or comprehend changes and decisions that needed to be made. Having doubts seemed to be an integral part of participants' work and this seemed to result in a reflective and collaborative approach that attempted to stay closely attuned to the behaviour of the person, while acknowledging own and wider limitations.

BETH: *It was emotionally challenging because this man he was just very often very upset, out of confusion, and it didn't leave you cold. You were so concerned about what might be wrong, are we doing everything we could be doing? He wouldn't be able to say and one needed to learn a certain confidence that we actually really tried everything, we can't really do more but it is hard to see.*

6.5.3 ‘Small’ discussion study three

Due to big changes in life expectancy and service provision for people with ID over past decades, there is increasing research but no clear conceptualisations of old age as a life stage for people with ID (Grant et al., 2001). Participants in this study conceptualised old age as a life stage similarly to professionals in a recent study by Johansson et al. (2017). It seemed that the change from middle adulthood to end-of-life could come quickly for some, while others seemed to experience old age as a life stage where they continued to be healthy and engaged in activities, but were getting tired more easily and enjoyed activities that were less physically or cognitively demanding. Participants described that it could be difficult, particularly in the beginning, to distinguishing between changes due to old age or disability-related impairments. Both communities seemed able to support people through changes in their routines and identities by creating more flexible and slower-paced routines. However, increases in challenging behaviour, absconding and medical needs were difficult to manage for both settings. In such instances tensions were identified between (i) minimising risks and ensuring that people were well and safe and (ii) making it possible for the person to stay within the environment, tensions that are reported within both the dementia and intellectual disability literature (Elliott et al., 2009, Lord et al., 2016, Webber et al., 2010). Participants highlighted how they struggled to make the decision for someone to leave the community, feeling that often people’s quality of life was negatively impacted. However, it appeared that relationships between the setting and the person often continued. Most participants had worked in the settings for many years, creating a sense of stability.

Overall, findings are more positive and stand in contrast to recent research that illustrates the difficulties of services to adequately support people with ID during the end of their lives (Lord et al., 2017, Todd et al., 2020, Tuffrey - Wijne et al., 2020, Tuffrey - Wijne and Rose, 2017). The unique set-up of both settings, and its focus on shared-community-living are likely to have contributed to a stronger emphasis on consistent relationships compared to findings from studies that are conducted in mainstream settings. Furthermore, both settings did not solely rely on shift-work, with shift-work being associated with less flexibility to respond in person-centred ways (Wiese et al., 2019). Interviews highlighted thoughtful practice and a commitment of

staff to support transitions in old age in person-centred ways. Staff and the people they supported had often known each other for many years and participants described their relationships to be similar to that of friends or relatives. Thus, the relationships described in this study challenge a strict professional view of 'service users' on one side and 'professionals' on the other. The theme of mutuality that was added to the grid stressed that participants believed that each person had value and was contributing to the community. Values discussed by participants bore great similarities to practices and values identified by Dossa (1990) in her study on the importance of meaningful relationships in the lives of people with ID in old age. Drawing on Bogdan and Taylor's (1989) 'sociology of acceptance' she identifies the importance of staff to (1) appreciate non-verbal communication and to be sensitive to intuitive elements within communication, (2) to view people as unique individuals and to have an understanding of their biographies, (3) to view relationships as reciprocal and (4) to value people's roles within their communities. Additionally, Bogdan and Taylor (1989) identified that believes in social justice or religious principles help staff to form reciprocal relationships and in this study both communities did promote an engagement with spiritual beliefs and the meaning of human relationships among their staff.

People with ID are often described as different due to their dependency on others (Kittay, 2001). While we might be under the illusion of being independent and autonomous human beings for most of our adulthood, Kittay (1999) describes how experiences of dependency are particularly evident for all of us at the beginning and at the end of life. Thus, old age was described as a stage where differences between the lives of people with and without intellectual disabilities were getting smaller. Participants made comparisons to experiences with relatives or friends without intellectual disabilities to stress similarities within the aging process, particularly when describing physical decline or dementia. Although people were described as needing more support in old age, participants emphasised that values of choice and participation continued to inform their practice. Involvement was facilitated through consistent and attuned relationships between staff and the person. Staff often needed to interpret behaviour, notice changes and facilitate new opportunities and routines for people based on knowing about their preferences and likes. The dilemma of not being able to fully know about the wishes and views of people was discussed. Close

collaborative practice and supervision seemed to be one way to discern the wishes of people. Overall there was less of a focus on external influences when discussing decision-making processes and practice. External barriers and influences were discussed, but solutions to most challenges seemed to be found within the setting. There was a focus on working across microsystems and involving those with immediate contact and knowledge of the person to respond to most situations. This might reflect a sense of having little agency and control over wider decision-making and finding it difficult to work with local authorities that are tied to budgets and fixed regulations. Participants' focus on working with people's immediate support networks could be interpreted as a response to a feeling of not being able to count on 'the system' for support. Involvement was also present in relation to end-of-life decision-making. Studies show that staff often feel uncomfortable to speak about death with people with ID (Tuffrey - Wijne et al., 2020, Tuffrey - Wijne and Rose, 2017). However, in both settings death was not seen as a taboo. Although participants stressed that it could be difficult to speak directly about individual people themselves or those close to them dying, both communities tried to create a culture that normalised death. Equally, Barton et al (2019) describe how it can be helpful to facilitate an overall awareness of death and to communicate that death is part of life to support people with ID within old age. Additionally, findings suggested close collaboration with local GP practices, regular check-ups and good access to health care for people. ID specific knowledge of health professionals and established relationships to health care professionals were noted as positive contributors, as has been suggested by others (Grant et al., 2001). There are different opinions if ID specific or general health services are best able to support people with ID in old age (Grant et al., 2001). Todd et al. (2019) call for the need for future research to clarify the role of both ID-specific and generic healthcare professionals to support people in old age. Participants in this study stressed the need to have both: professionals with specific knowledge of physical and medical care, as well as professionals with ID specific knowledge to support people's communication.

The historic context and changing attitudes about the inclusion of people with ID is important to mention in relation to the involvement of people and their families within transitions in old age. People currently in their mid-fifties or older seemed to have had

little family contact throughout their childhood and adulthood and could be living far away from their original localities. It was suggested that this seemed to slowly change with newer generations having closer family involvement and stronger connections to families and local networks, with siblings being described as taking on guardianship and becoming closer involved in the lives of their brothers or sisters in middle adulthood and older age, as parents are aging or have passed away (Davys et al., 2015, Taggart et al., 2012).

Themes within the first two layers provided richer data compared to the consequential layer. Using a consequential or utilitarian perspective to moral reasoning has been widely criticised within disability studies. The critique focuses on narratives that portray people with ID as burdens to society that take up resources (Kittay, 2009, Vehmas, 1999). In this study such narratives were missing from interviews. Within the consequential level participants focussed on consequences for the person, themselves or the setting, leaving out consequences for society. Overall, participants took a relational perspective when discussing their actions and decisions made, highlighting the specific and unique context of each individual and their relationship to them. Thus, the actions and thoughts of participants seemed to align more closely to an ethics of care perspective rather than consequential or deontological theories, as they are used in Seedhouse's grid. Deontological and consequential theories attempt to make ethical claims and develop imperatives that are absolute, while ethics of care is concerned with particular relationships and specific contexts, highlighting the human dimensions of ethical decision-making (Dunn and Burton, 2008, Reamer, 2016).

7. DISCUSSION

This chapter looks more closely at the findings across the three studies and discusses them in light of existing theories and research. In the first part of this chapter I explore in how far people with severe ID were involved in decision-making processes. Furthermore, I examine influences across ecological levels, illustrating how transitions were shaped by resources available in local areas, organisational practices, policies and cultural beliefs. While the focus of the discussion will be on the transition journeys of people with ID and their involvement in decision-making processes, I also turn to the experiences of family members and professionals to highlight how their own circumstances, needs and views in turn influenced the transitions of people with ID. In the second part of the chapter, I turn to questions that I identified in relation to caring, belonging and responsibility. Here I look at care as a complex concept that does not only connect to practical support and assistance, but touches on emotional spheres of caring, highlighting close human relationships that are formed between people who care for and about each other (Rogers, 2016). Thus, the second part of the chapter will speak to the worries of parents about what happens when they are no longer alive or able to be actively involved in the lives of their children. I question if services can become places of belonging for people with severe ID and if professionals can become friends or even family.

7.1 Who decides?

Throughout this section I draw on the concept of interdependence to theorise how decisions were made and to understand how people were involved in their own transition journeys (or not). I will draw on the concept of interdependence to challenge narratives that negate the possibility for people with severe ID to be meaningfully involved in decision-making processes. I believe that the concept of interdependence enables me to untangle some of the complexities that were inherent in the accounts of participants across my three studies, accounts that described possibilities for involvement by seeing behaviour as communication, but that also highlighted difficulties and tensions in determining what would be in the person's 'best-interest'.

All three studies showed differences between the involvement of people with severe ID in their immediate environments and on wider levels. Attuned and consistent relationships seemed to facilitate participation in people's microsystems. However, moving from people's Microsystems into Exo- and Macrosystems highlighted a lack of involvement and participation of people. Thus, in the second part of this section I will draw on the writing of Smith (1990) and Altermark (2016) to explore the roles that ideologies and political practices play in excluding groups from society from a feminist (Smith, 1990) and a disability (Altermark, 2016) perspective. All participants, professionals and family members, and I as the researcher, experienced a sense of disconnection when comparing official policy documents with the transition journeys of the people in this study. By drawing on both writers I will attempt to make sense of the gap between the ideals of policies, and actual practice. Smith (1990) calls this sense of disconnection '*experiences of rupture*' that make apparent the mismatch between ideologies that are promoted at a policy and cultural level and the everyday experiences of people. I believe that the concept of interdependence can help us to reconnect and bridge the divide between ideals and practice.

7.1.1 Interdependence – reconceptualising involvement

My daughter or son can't speak, and I am them (...). (Team leader support organisation for parents; study two)

Across the three studies participants differed in their conceptualisations of how people with severe ID are, or can be, involved in transitions. For example, all mothers, except Peter's mother, described at some point during our interviews how their child was unable to be involved due to their inability to understand abstract concepts. Additionally, some mothers excluded their children from the proximity displays that focussed on involvement in the transition. Yet, at the same time it was apparent in our conversations how all mothers saw their child as a person able to express their views, feelings and preferences, stressing the importance of knowing them well to be able to 'listen' to them. Thus, communication and participation were seen as achievable through attuned relationships. The difficulty of answering my question about involvement seemed to be connected to an unconscious inference that I was asking about involvement based on verbal interactions. Other participants however directly conceptualised involvement in a relational manner. This was most apparent across

interviews in study three, where participants described how decision-making and involvement were based on trusting relationships, knowing the person well, close observations of the person's responses to different environments, closely working with others who knew the person well and understanding their relationships with people as reciprocal. Similarly, Luke, Ben, Peter and Emma's adult services talked about involvement from a relational perspective. I believe those accounts show how involvement of people with severe ID can be understood through the concept of interdependence, instead of stressing either independence or dependence.

Interdependence is a prevalent concept used in the writing of feminist and disability scholars. The concept stresses that human beings are inherently social, deeply vulnerable and dependent on others throughout life (Malleson, 2017, Rogers, 2016). It might seem that the theory of interdependence does not offer anything exceptional, that it describes something that is common-sense to most people. Malleson (2017) argues, on the contrary, that although most would agree with the basic beliefs of interdependence, the dominant cultural beliefs of western society and the way the economy and our institutions work, continue to reflect the opposite, and are based on a liberal view of humans as independent and autonomous beings. Malleson (2017) claims that if we truly understand our lives through interdependence, we would need to re-evaluate and transform our cultural beliefs, political concepts and institutional practices. He builds his argument around Freud's (1935) historic inquiry into major changes in people's understanding of society, their relationships to themselves and the world around them. Freud (1935) names three such events; (1) the discovery that the earth was not the centre of the universe, (2) the theory of evolution, which found mankind to have its origin in the animal world instead of being created in the image of God, and (3) psychoanalysis challenging the view of the rationale and conscious mind by exploring the role of the unconscious in guiding our actions. Malleson (2017) identifies interdependence as the fourth challenge to existing beliefs and structures. He writes about interdependency:

We have not yet grasped the significance of its truth. We have not yet seen how deeply it undermines various beliefs and practices. At the same time, we both know it and ignore it. In this, our culture suffers from profound cognitive dissonance if not willful ignorance. (p. 161)

Differences between accounts of participants that negated the possibility for people with severe ID to be meaningfully involved in decision-making processes and those that stressed relationships as the basis for understanding and involving people arguably reflect the dissonance Malleson (2017) speaks about, a dissonance that was present in many, but not all interviews. Dissonance showed in participants being aware of the importance of relationships and support networks, while still comparing the person with severe ID to the 'ideal' image of the rational, independent human being, and thus judging the person to be lacking and incapable of being meaningfully involved in decision-making processes. Thus, there seemed to be a disconnection between conceptualisations of involvement and the actual practices I observed, and participants talked about. Looking at the immediate environment of the person, my data showed how the person was often involved and how family members and education and social care professionals showed the importance of being responsive and attuned to the person, and seeing their behaviour as communication. The relational nature of participation has been emphasised by others (Dennis, 2002, Johnson et al., 2012, Simmons and Watson, 2014, Kruithof et al., 2020) but similarly to this study those close to the person with severe ID who find themselves in the role to advocate on behalf of the person, and to facilitate their involvement in daily life, discuss the complexity of doing so. In the following I will identify three complexities that were discussed across the three studies and I will show how the concept of interdependence might help to solve some of the tensions.

7.1.1.1 Best interest vs. preference of person

The tensions and complexities inherent in best-interest decisions are widely discussed in the field of ID (Altermark, 2016, Bigby et al., 2009, Wagemans et al., 2013). Tensions can relate to caregivers believing that a certain course of action, lifestyle choice or treatment will be beneficial for the person's wellbeing and their quality of life, standing in conflict to preferences that are indicated by the person's behaviour. Thus, complexities respond to issues of power and inequalities in who has the last say and whose perspective is given more weight. Such conflicts were apparent in my data in relation to food choices or physical activity levels being deemed unhealthy, with education and social care professionals and parents feeling responsible to encourage healthier food choices and more active lifestyles. Additionally, social care professionals spoke about the complexity of widening people's access to activities and

experiences and how to respond to people's initial refusal or reluctance to try out something that was new and unknown to them.

It might be easy to draw a picture here of caregivers as the ones with power, imposing their own values and views on the person who receives care, painting yet again a picture of the person with severe ID as passive. I believe it is important to take power inequalities within caring relationships very seriously and tragically there are still too many occasions where caregivers misuse their power (Altermark, 2016). However, my data showed that the relationships between people could not simply be described within a paternalistic framework. My observations and interviews demonstrated how many accounts of professionals and parents validating the person's communication, showing that they had listened, even if they did not agree. For example, when we went for a walk with Ben at the seafront he asked to sit in his wheelchair after a few steps. His support worker acknowledged his request but encouraged him to continue to walk with us, offering him to hold on to his wheelchair for extra support or keep holding her hand. He chose to hold her hand. When he asked to sit again a while later, she then agreed and he sat in his wheelchair for the rest of the walk. Interpreting her actions as an example of how Ben was treated as a 'child', while she was in the position of power, draws on the opposites of dependence and independence, of needs on one side and rights on the other. Interdependence instead focuses on the relationship between both people, looking for the presence of respect, attentiveness and trust. Thus, a relational perspective is able to capture how the interaction between two people can include both: having concern for the wellbeing of the other, being aware of their needs, as well as listening to their choice and seeing them as active agents able to express their views. The validation of the person as a partner within interactions, was similarly apparent in my observation of Lisa's support worker trying to encourage her to join the music session that was taking place in another room or Luke's adult service encouraging him to join others for group activities. Participants across the three studies were able to see behaviour as communication, but many reflected that some behaviours could not directly be translated into choices. For example, people with severe ID showed their dislikes or likes within the present moment, their responses were often bound to their immediate experiences. Lisa refused to walk into the music room because she found herself in the café, a place she knew and liked. She might have enjoyed the music session, had she been in the room, and her support worker

was confronted with the complexity of how to communicate what was happening in the other room to her. If we look at this interaction through the lens of interdependence, we will see how both Lisa and her support worker are responding to each other, with the support worker trying to explain to Lisa why she is encouraging her to go to the other room. She takes a music instrument out of the room to try and build a connection for Lisa. Even if unsuccessful it shows how she is trying to communicate back to Lisa. Equally, in relation to tensions around medical treatment, diet or lifestyles, participants in all studies gave examples of trying to communicate the importance of treatment, hygiene or healthy eating to the person through the use of social stories, by using body language and working with the person's environment. Participants took the time to explore if the observed behaviour really did indicate a dislike for a certain activity or if it was anxiety about starting something new, a response to a sensory input or a change in routine. Thus, many of the relationships I observed between people, and the way participants spoke about their role in facilitating 'best-interest' showed sensibility and attentiveness. Dennis (2002) discusses how respectful relationships and a commitment of professionals to listen to the person are able to navigate power imbalances. Thus, by taking a relational view people are seen as active agents, and those close to them are able to facilitate their involvement by 'listening'.

7.1.1.2 Interdependence of lives of caregiver and cared-for

All three studies reflected the interdependence of the lives of people with severe ID and those close to them at times of transition. Not only the needs and preferences of the person, but also those of main caregivers influenced what happened. Writers within disability studies have criticized the priority that is often given to the voices of 'care-givers' in research that explores care relationships (Graham, 1993, Porter, 2006). The focus on the experience of caregivers risks creating a picture of those being cared-for as passive, 'needy' and burdensome, while glorifying caregivers as committed and selfless (Rogers, 2016), leaving no space for seeing the cared-for as participating and being equal members within the caring relationship (Barry, 1995). My own data showed the complexity of differentiating between the needs of the person and those that were living and working alongside them. Instead of portraying people with severe ID as passive care-receivers and parents and social care professionals as active caregivers, it appeared that the lines were more blurred. Taking a relational

perspective showed how not only the 'cared-for' had needs, but likewise carers had needs and required support. Thus, if we understand care-relationships through the lens of interdependence we can see that we are all in need of care, challenging the neat dichotomy of givers and receivers (Porter, 2006). Moreover, interdependence highlights the political dimension of care by making apparent the need for appropriate resources and support to be allocated to those who provide care (Tronto, 1993).

The interdependence of lives of parents and their children was particularly striking in the cases of Emma, Tom and Lisa, who all still lived at home. Hopes for the future lives of their children were closely intertwined with what parents hoped and wished for in their own lives. Particularly the lives of mothers were greatly influenced and shaped by their role as main-carers. Looking at the relationships of mothers and their children through the lens of independence risks seeing their needs as conflicting. We might see individuals, with rights to an autonomous life, rights to pursue their interests, the right to work, casting the child with severe ID in the role of denying their mothers the same freedom others enjoy. Yet, as Porter (2006) writes, through interdependence it becomes clear how highlighting the caring-cost on women – or men – does not negate the value of the caring relationship and the emotional attachment that is experienced. On the contrary, it problematises that caring-work continues to be firmly located within the personal realm and people's microsystems (Rogers, 2016). The three studies highlighted that it was often close personal relationships that had formed between caregivers and cared-for that allowed someone to stay at their home or service. It was committed individuals who listened to the person and cared about them, not a caring and responsive system and in all three studies a common statement that was made by parents and social care professionals was '*we do it, until we can't do it anymore*'. Those statements emphasised the lack of adequate support and resources available to those in caring roles. For example, while social work assessments took account of the needs of parents beside the needs of their children, Emma's parents were repeatedly told that Emma was not a priority to receive a place within supported living. Tom's mother was committed to look after him at home '*until we are too old and too decrepit to look after him anymore*'. Yet, her respite allocation was cut substantially as he transitioned to adult services. In study three professionals supported Gary to stay within the community, dying surrounded by those who knew him well, despite additional funding from social care being slow and unable to respond in time to his

changing needs. The lack of support for carers had several consequences in relation to transitions. Firstly, it promoted a practice driven by crisis, and secondly, it put parents and social care professionals in the position of having to emphasise the impairment of the person, to emphasise difficulties to ensure they received support. Taking a relational perspective shows that there was not only a lack of choice for the person, in terms of services and available support, but inevitably also a lack of choice and alternatives for the 'carers', a lack of support for them. A true acknowledgement of interdependence lifts care out of the personal, into the social and political domain (Sevenhuijsen, 1998). Yet, my data mirrors other research within the field of disability and social care that shows how facilitation of involvement and the responsibility of care continues to be too often transferred to individual people, families and social care services (David, 2016, Porter, 2006).

7.1.1.3 How to really know?

Across the studies family members, education and social care professionals spoke about the difficulty of making inferences about people's views and preferences based on knowing and observing them. Participants showed an awareness of power imbalances and the ethical dimensions of facilitating involvement. An understanding of humans as independent and rationale beings sees capacity as an intrinsic characteristic, one that is lacking in people with severe ID (Haslam, 2012). I will argue that interdependence on the other hand will allow for doubt, will even see doubt as something positive, as meaning is made relationally and collectively. Following Haslam (2012), making the shift from capacity to relationality allows us to affirm the human status of people with severe ID and to promote inclusion and participation. While there will always be ethical challenges and dangers involved in making inferences based on nonverbal communication, Haslam (2012) believes that the risks of excluding and further marginalising people with severe ID by staying silent is far greater. To understand the role of communication and involvement in her work as a therapist working with people with severe ID she draws on the philosopher Martin Buber. Buber (1958) claims that human beings can only be understood as participating in and through relations. When people interact they turn towards each other, value the other and recognise the other as a human being in the immediacy of the moment that is experienced by both (Haslam, 2012). Knowing and communication are not framed within a 'subject' and 'object' structure, where the person without ID (the subject) is

seen as imposing meaning on the person with severe ID (as the object). Instead interactions between people are described as intersubjective. While all experience is seen as subjective, influenced by one's cultural context, assumptions and values, it is created in relationships that involve two (or more) subjects, who co-create meaning together (Capri, 2014).

Participants who had a close involvement in the lives of people described the process of trying to understand the person in similar terms to those of Haslam (2012), equally stressing the immediacy of communication and experience. People were seen as responding differently to and acting differently in different environments. Thus, across the three studies the importance of collaborative practice was emphasized to be able to question each other's interpretations and create a more holistic picture of the preferences of people. Similarly, Simmons and Watson (2014) describe that a collective approach to 'meaning-making' can facilitate the inclusion of people with severe ID. In their ethnographic study with a youngster with profound and multiple disabilities, Simmons and Watson (2014) illustrate how a relational approach and an engagement with significant people in the young person's life, aided an understanding of the person's multifaceted identity.

7.1.1.4 Concluding remarks

Malleson (2017) connects the concept of interdependence to Bronfenbrenner's ecological theory. He argues that most of us would create a lone figure if being asked to draw an individual, representing the 'myth' of independence. He argues that through the lens of interdependence we would see the figure within a circle of circles, illustrating that people only exist in social environments spanning immediate relationships, institutional practices, politics, economy and culture. Interdependence does not only emphasise the relationships people have in their immediate settings, but it asks us to explore how organisational structures and cultural beliefs govern who has power and who is given priority. If we understand participation through interdependence, then it becomes clear that the relationships people have in their microsystems will be key to facilitate involvement and social inclusion on wider levels. My data showed that involvement and participation was possible in people's immediate environment and it was achieved through the relationships people had with family members and professionals. Additionally, it showed that a relational perspective

creates the possibility for advocacy, which poses the question how much parents and others close to the person were involved and listened to (Kruithof et al., 2020). Thus, in the next section I will turn to the socio-political sphere to explore how people were involved and decisions were being made.

7.1.2 Gaps between ecological levels – a sense of disconnect

The difference between the reality and what is being presented and what is said has never been as wide as it is now, ever since I am involved in this work, and that is forever. (Peter's adult service admission co-ordinator, study one)

During the process of data collection and analysis I struggled for a long time to connect different parts of my data. I interviewed social workers and local authority professionals to try and understand how organisational practices and policies influenced their work. I traced local authority policies, reports on transport budgets, reports on the number of people in out-of-area placement and local authority strategies that set out how to mitigate a reduction in available budgets with an increase in demand. While I started to understand how budgets, available resources, local authority priorities and organisational practices influenced transitions, I suddenly found myself far removed from the young people and adults, who were supposed to be at the centre of this study and the transition process. I felt a great disconnect between my observations, talking about the person in interviews, and my data that explored influences within Exo- and Macrolevels. While I was able to see how people were involved in their Microsystems and on a Mesosystem level, they seemed to disappear as I moved to explore the Exo- and Macro. This sense of disconnect seemed to operate on two different levels. Firstly, national policies were advocating early planning, individualised support and choice, while my data showed a turn to crisis-driven practice, lack of options and a reduction in budgets. Secondly, policies placed the person with severe ID at the centre of the process, highlighting the person's rights, yet in practice I found an emphasis on people's needs and their vulnerability. It seemed that I was not alone in my experience of disconnection. In my interviews, local authority professionals and social workers often described the principles that were supposedly informing their work and then following this by saying '*but in reality*', and then speaking about reductions in services and finances.

Altermark (2016) criticises how divides between policy and practice are often simplified. The ideals of policies are upheld and the divide is blamed on poor implementation and professionals being unable to understand or follow policy guidelines. He believes that the problem is more complex, as ideals of citizenship, independence and self-determination continue to fail to be implemented across western countries. He writes:

We see processes of deinstitutionalisation, socially integrated living arrangements, legal frameworks granting individual rights, and commitments to 'independent living' and 'self-determination', across national borders and in the work of influential international organizations such as the UN and the WHO. At the same time, however, the results of inclusion are far less rosy than the stated ambitions: it seems that people with intellectual disabilities are far from the self-determined citizens, participating and fully included, that the new policies postulate. (p. 14f)

Altermark (2016) argues that paradoxically the ideals of self-determination and independence, which were used as reasons to exclude people with ID during the time of institutions, are now used within a rights-based framework to advocate for their inclusion. In his analysis of the inclusion of people with ID as citizens in the era of 'post-institutionalisation' he emphasises how a move towards rights promotes for people with ID to live lives as everyone else, while people with ID are simultaneously still seen as different. Thus, society ends up including and excluding people with ID at the same time. Altermark (2016) goes on to conclude that the inability of our current ideologies to meaningfully include people with ID can be used as a starting point to critically examine them. In a very similar vein, Smith (1990) writes about a disjunction between the concepts and ideologies that prescribe what is important in this world and how people experience the world. She builds her argument from a feminist perspective of women as a marginalised group, living in a world governed by men, but her writing mirrors many tensions identified within disability studies, that see people with ID living in world that has able-bodied, rational and independent people as their ideal of 'good citizens' (Rogers, 2016, Malleon, 2018). Smith (1990) argues that it is during moments of rupture between the conceptual world and our experiences of the everyday world that it can become clear how the conceptual world, the world of ideologies, is not reflective of the lives people live, thus resulting in a realisation that we need to change the concepts that underlie the structures of our practices. In the following I will

identify such moments of rupture within my data and consider how interdependence might be able to build bridges between policy and practice.

7.1.2.1 Disconnect between ideologies of policies and available resources – setting people up to fail?

I think their hands are tied as well. It is all money isn't it? It is all you know what funding do we have available. (Tom's teacher, study one)

Across the studies transitions were multidimensional in nature, involving decision-making processes on different levels. There was a clear indication that people were involved in the practical parts of transitions and that they were listened to by those in their immediate environment. However, exploring the organisational parts of the process showed a different picture. The CRPD (United Nations, 2006) calls for an active involvement of all persons with disabilities in decisions that affect them, seeing participation not solely in relation to people's involvement in their microsystems, but stressing participation across ecological levels including participation within policy-making and service provision (Löve et al., 2017, Mittler, 2015). My studies add to the evidence that people with ID and their families are largely excluded from decision-making processes on wider levels (Löve et al., 2017). Yet, my data further showed that not only family members but likewise professionals, including support workers, teachers, social workers and local authority managers, felt that '*their hands were tied*', and that they needed to work with what was available. Across the three studies a picture emerged of people acting within a system that made it impossible for them to meet the ideals that were promoted by current policies.

Interviews, and most notably the proximity displays, showed how those close to the person were routinely involved in practical questions, supporting the person to move into a new service in the best way possible. This occurred once decisions about placements and funding had already been made. While teachers or support workers were involved in early review meetings to help create a sense of the preferences and views of the person with severe ID, those meetings were seldomly linked with a discussion of available services, budgets and resources. Education, health and social care professionals reported that they felt they had little involvement or power to influence what was decided. Similarly, in study three social care professionals focused

on how they supported the person, and each other, within the immediate setting of the community, while reflecting that decisions about funding or outside support were largely out of their hands. This mirrors findings of research on person-centred practice (PCP), which has found that detailed knowledge about a person's interests and preferences has often little influence on operational aspects of service provision, such as service commissioning (Cambridge and Carnaby, 2005, Small et al., 2013). Thus, my study mirrors the findings of past research that transition planning emphasises involvement foremost in relation to the physical move from one setting to another (Cox, 2017, Jindal-Snape, 2016). Within a social care system stretched to its limits few options are available, resulting in decisions being made based on what is available (Hardy et al., 2005). Small et al (2013) argue that in relation to transition planning, person-centred approaches currently only *'prepare young people for transition into existing services in a person-centred way, not plan a person-centred service'*. (p. 285) A statement that rings true in relation to the transition journeys that were examined in this thesis. Correspondingly, Burton and Kagan (2006), in their scrutiny of the Valuing People policy of 2001, describe *'a kind of romanticism about learning disabled people'* that simplifies challenges and remains silent about the financial resources needed to put ideals into practice. Small et al. (2013) criticise that while policies acknowledge the importance of the wider social context in the lives of people with ID, practice continues to be individualistic in nature. They argue that PCP needs to be integrated within an ecological framework that highlights interdependence to connect people's microsystems to wider levels. Equally, a recent report on SDS in Scotland highlights that local authorities and service providers struggle to be person-led within the current funding climate (SDS Consortium, 2005), reflecting that a system, which does not provide the needed resources and continues to be budget driven, is unable to provide true choice and person-centredness.

7.1.2.2 Living a good life is living a 'normal' life?

Smith (2008) argues that a focus on rights and access, as advocated by the social model of disability, can risk creating a picture where disabled people are seen as striving for a life where they can participate in the same ideals that 'normal people' are supposedly enjoying. He describes how this creates an essentialist view of normality and abnormality, and independence and dependence. Similarly, Altermark (2016) argues that current policies infer that the goal for people with ID is to live 'normal,

independent lives', thereby trying to include people in an ideology that is unattainable for them. Primarily in study one and two my data illustrated how professionals' values and beliefs about 'normality' influenced their judgements on how a good adult life should look like for people with severe ID. This seemed to be connected to people at times struggling to take the perspective of the person with severe ID and what they knew about them through their daily interactions. This was most apparent in a number of interviews in which professionals talked about people's rights to live independently in their own flat. For example, Emma's teacher voiced his regret that Emma would never be able to live independently.

It is difficult for me don't get me wrong I would love every kid to be able to move on to something like that, but it doesn't strike me as something that she would be able to do which is a shame. (Emma's teacher, study one)

Yet, asked if he thought Emma would want to live by herself, asked to take her perspective, he referred to his previous observation how she seemed to thrive in group environments and loved social interactions.

That is a very good question. Part of me hopes that she would say no because as I say, I think she does, she can really come out of her shell. (Emma's teacher, study one)

His earlier argument mirrors a top-down approach, where views and decisions are based on ideology, instead of knowledge of the person's preferences and their everyday reality. Narratives that emphasised people's rights to be independent seemed to be connected to a wish to distance current social care practice from the past of institutional care, which has been found by others (Gleeson and Kearns, 2001, Jingree and Finlay, 2012). Björne (2020) draws on the work of the philosopher Appiah (2017) to argue that practices, which promote for people with ID to live 'normal lives' within supported living settings, are a simplified idealisation, which serves a political purpose '*known to be false, yet used as if it were true*'. (p. 2) Björne (2020) discusses how an idealised picture can be helpful to promote the rights of people, but that it can also be dangerous in instances where the gap between ideals and the reality of practice has substantially widened, masking how practice is in fact moving further and further away from the desired outcome. The danger of a widening gap between ideals and practice was probably most apparent in the example that was given by the project manager of a local support service in Lisa's local authority. He discussed how the move away from larger group accommodations had been positive, enabling people to

be more independent. Yet, referring to the example of a young woman who received support from the service, he went on to say:

There is one where we are currently sort of whittling back and she is now, she went from having a sleep over to not having a sleep over and we are reducing her support as well. But she has autism and she is incredible vulnerable, and she is not able to go out of her flat herself. So, the thing about it is, that it is very good that we are reducing the support, but it also limits her access to the community, because she can only really do stuff when we are there with her. (Adult service team leader, Lisa's case, study two)

In this example, within a climate of reducing resources, the ideal of independence is used as a reason to withdraw support, leaving the young woman more isolated and more excluded. Similarly, other professionals (the manager of Ben's local authority, Ben's adult service team leader and Emma's social worker) described that a move towards single tenancies in the era of post-institutionalisation had gone hand in hand with a decrease in funding and resources. This meant that in practice people were often supported by staff who were working long shifts, without supervision, resulting in less support for staff and a higher potential for victimisation of people with ID, particularly in services with high staff turnover. While better quality of life has been associated with smaller group home settings, single tenancies or core and cluster accommodation (Bertelli et al., 2013, Emerson et al., 2000a, Marlow and Walker, 2015), research also points to the importance of the quality of one to one interactions, staff culture, staff values, effective leadership and organisational support for staff within those settings to facilitate 'good lives' (Bigby and Beadle-Brown, 2016, Bigby and Beadle - Brown, 2018, Humphreys et al., 2020). My data showed that those closest to the person, family members and key-support staff, highlighted that quality of relationships and access to activities within people's microsystems were decisive factors for a good quality of life. Focussing on people's immediate environments helps to highlight that quality of care can vary across different service models and within the same organisation (Bigby and Beadle - Brown, 2018, Heller et al., 2002). Thus, deeming one service-model better than another can be argued to again reflect a top-down approach, without regard for the preferences of the person, relationships in the person's life and without linking it to the necessary resources to achieve good quality of care.

7.1.2.3 Disconnect between needs and rights

In his analysis of the Swedish disability context, Altermark (2016) identifies a disconnection between right-based policies and a practice that continues to be based on people's needs. He writes:

(...) to be eligible for special services that should produce independence, one has to be considered as someone in need of help. As we shall see, post-institutionalisation is frequently haunted by such contradictions and conflicts between designations of otherness and dreams of inclusion. (p. 17)

In my interviews there were similar accounts where participants moved from a rights-based narrative, stressing people's rights to choice and independence, to one that emphasised people's vulnerability and needs. Furthermore, my data highlighted that while rights were advocated for on a policy level, the practice of assessing people's eligibility for support, determining who had priority to access the limited resources available, was based on people's needs. Particularly in study one and two, I felt that tensions between limited resources and competing demands led to the risk of an emphasis on people's difficulties and a danger to focus on people's impairments, thereby losing the person in the process. This was particularly striking in the cases of Emma, Tom and Luke. To ensure Emma's family would receive substantial support, her social worker assessed her level of need as critical. When it came to her transition from children to adult respite services, the category 'critical' that had been given to her, informed the decision to place her at a respite service, which both her social worker and her parents deemed to be unsuitable for her. Her social worker argued that Emma would benefit from visiting a smaller service '*for more able adults*', but the service was seen as incompatible with someone of a critical level of need. Thus, the category swallowed Emma the person. Shortly after, Emma 'disappeared' again. Feeling that they were losing the vital support that allowed their family to cope, and feeling pushed to their limits, Emma's parents ended up 'threatening' social work '*to give Emma up*', while simultaneously stating they could never forgive themselves for doing so. It was clear that this was not in Emma's best-interest, nor was it a decision that took her views into account, instead it objectified her and took away her agency. A crisis was prevented once social work agreed to fund transport to Emma's respite. In both Luke and Tom's case there had been incidents that involved challenging behaviour. It seemed to be difficult for professionals and myself to balance an acknowledgment of the seriousness of the situation, without stigmatising both young

men as 'dangerous' or 'vulnerable'. While reflecting on my own experiences of spending time with Tom and how people talked about him in interviews, I noted that there seemed to be two narratives, those that focussed on his abilities and those that emphasised the difficulties of supporting him through phases of severe self-harm. Overall, there was a tendency to focus on his vulnerability, but his teacher and his adult service team leader both focused to the same extent on his strengths and involvement in activities.

He is an amazing PECs user (Picture Exchange Communication). Possibly one of the best in the school. (...). He is very good to make choices at request. He can make a few part sentences "I want a cuddle from [X]" and he is very good at using that. (Tom's teacher, study one)

There is an art class that he's really enjoying. I think he is creating a canvas at the moment. His art is really interesting. It is lovely to see him. It is really meaningful and enjoyable because he always sings when he is creating things, it is really lovely. (Tom' adult service team-leader, study one)

Being confronted with both narratives was difficult for me and in the beginning, I had the urge to focus on Tom's strengths and abilities and less on narratives of hardship and concerns about his wellbeing. Then, during my observation at his class I witnessed him becoming distressed.

In class Tom sits at his desk. (...) He has his face pressed into a cushion that lies on top of his desk, with a soft blanket on top of the cushion. He is holding both hands close to his ears. In his right hand he is holding a picture. His back is slouched and under the table his legs move from side to side. His knees touch and then swing back and forth. (...) It has been 20 min. Tom is still burying his head inside the cushion, while his classmates watch a movie. The movie finishes and a class-helper puts a timer on to the pillow next to his head while his class mates go outside for break time. Another class helper sits next to him and she puts her face on to the pillow beside him and says softly: "Hi Tom". He turns to the side, smiles and says "Whoo". Then he turns his face back out of sight (...) The timer beeps. Tom gets up abruptly and fast. The class helper holds his timetable book in front of Tom and he puts a sign from his timetable in the provided 'finished box'. His fingers move carefully and his movements of hands and arms are minimal. Then he follows the class helper a few steps into a cosy corner of the classroom, full of pillows and cushions. He lies down covered in a blanket and his class helper puts on a story and music. (...) Later on, after break time, while Tom is back at his desk another pupil close to Tom starts to jump and shout. Tom starts to cry. His mouth faces down and his eyes turn red. He closes his eyes and cries. While he cries he remains sitting up straight. His class helper next to him strokes his back and tells him that he is fine. She presses the sides of his arm. (...) Tom continues to cry throughout the next activity and starts to rest his head again on the pillow on top of his desk. I

am finding it uncomfortable to watch. I am focusing less on Tom and watch around the class. I feel it is not appropriate to stare at him and note down his distress. (observation vignette, Tom's case, study one)

I felt that I was witnessing a private moment, that I did not want to emphasise a narrative of personal tragedy, that Tom was more, he was someone who enjoyed art, music, someone who had formed close relationships to many people in his life. Yet, I was also aware that Tom's change in moods and his self-harm were big parts of his life and the lives of those close to him. I was left unsure how I could include an account of Tom's needs and difficulties without creating a one-dimensional picture of him. Only later on, during the data collection process in study two through my involvement with Luke and his mother could I see how an emphasis on needs did not necessarily need to mean losing the person in the process. I was impressed by the clear vision of Luke's mother and his day service that the incidents that had occurred should not result in an exclusion of Luke from society. Instead, an argument was made for him to receive more support to allow him to continue accessing activities. The argument that was made in Luke's case acknowledged the interdependent nature of 'independence'. To allow him to remain independent he received more support. As Malleson (2017) argues, to increase people's independence and freedom they often need the exact opposite, that is '*(...) not being left alone, but being supported, aided, fostered, nurtured, or empowered*'. (p.172)

Luke's mother and his adult service used a rights-based approach to argue for his **need** for more support to allow him to be free and included. In his case rights were closely linked to needs. Similarly, Mietola and Vehmas (2019) in their ethnographic study on what constitutes a good adult life for people with profound ID in supported accommodation, found that support workers were able to draw on a rights-based narrative to highlight where a person did not have access to opportunities they should have had, such as meaningful activities, vocational work or peer interactions. If rights are linked directly to the person and work from the bottom-up, they can help highlight injustice (Rogers, 2016). Furthermore, thinking back to Tom, connecting rights and needs helped me to understand that people are not either vulnerable or active agents, but often both at the same time.

7.1.2.4 Concluding remarks – the importance of everyday knowledge

When I reflect back because I know the man now so well and I think he is happy. (...) I didn't necessarily see the unhappy man. I saw the challenges that it was for me and my service and the team, but on looking back (...) I can see the sort of unhappiness. (Ben's adult service team leader, study two)

Reflecting on Ben's transition from home into supported accommodation his team leader expresses the risk of focussing on people's impairment or difficulties in the absence of established relationships. Her reflection emphasises the importance of knowing people to be able to facilitate their involvement and to be able to truly listen to them. A close examination of my data across the three studies demonstrated that people with severe ID can be involved in transitions, if involvement is understood relationally. To be heard and understood the person relies on relationships to others and continuity in those relationships, which highlights the importance of advocacy in the life of people with severe ID (Gleeson and Kearns, 2001, Kittay, 2001, Kruithof et al., 2020, Ledger, 2012). Although my time spent with each person only offered me a limited glimpse into their life, those hours were valuable to meet the person and to learn more about their way of communication (Oulton et al., 2018). Within their immediate setting people were clearly making choices and had a degree of agency. Yet, many key-events and decisions were made without the person being present. Thus, it is important that those that are involved in making decisions have an awareness of the person's responses to different environments, bringing together people across the person's microsystems to inform a bottom-up approach to transition planning.

7.2 Who cares?

That really doesn't matter to anyone else and in a sort of roundabout way it is no one else's fault, but in another way society is, (...) they are putting back disability, they are going back the way. (Emma's mother, study one)

In this section I turn to care and caring and draw on writers within the ethics of care tradition to explore the caring relationships that were visible in my data. I explore care not only in relation to the practical activity of providing care or support, the realm of caring **for**, but will also think about care in relation to caring **about** people, which Rogers (2016) and Noddings (1999) identify as the emotional realm, the realm that describes being concerned about someone, feeling responsibility and commitment.

Rogers (2016) identifies three spheres of caring: (1) the emotional caring sphere (*where love and care are psycho-socially questioned*), (2) the practical sphere (*where day-to-day care is carried out relationally*) and (3) the socio-political sphere (*where social intolerance and aversion to difficult differences are played out*). She argues for the importance of lifting care out of the private realm and to critically examine where society places care and how care is valued. Alongside 'care' I will introduce the term 'belonging' to emphasise that relationships people had to each other included both emotional commitments, the caring **about**, as well as practical aspects of providing care **for** people.

7.2.1 People's sense of belonging in the immediate environment

The concept of belonging has started to gain popularity and is now used alongside a focus on participation by the CRPD (United Nations, 2006) who state that'

the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging (p. 6).

The concept of belonging has been used to facilitate a deeper understanding of social inclusion, one which stresses the presence of close relationships to others and the attainment of valued social roles within society, instead of merely calling for people's physical visibility within local communities (Power, 2013). As Power (2013) writes:

Belonging thus does not solely involve being placed within an environment, but fitting in within a specified place or environment. (p. 69)

His conceptualisation mirrors those of participants in my study, who stressed the importance of people having access to meaningful tasks and activities and for people to feel welcomed and accepted. All mothers spoke to different extents about the difficulty of finding places that accepted their children and did not see them as different, describing how their existing residential, supported living, respite and day services could offer places of belonging. Mothers described that in those settings their children were known and appreciated as valued members of the service. Similarly, in study three participants spoke about facilitating and respecting the sense of belonging people felt to living in the therapeutic community, stressing that it was their home. Across my studies there was evidence that young people and adults had close relationships to others in their life. Yet, my findings were somewhat antithetical. The

three studies confirmed research findings that describe the narrowness of support networks available to people with severe ID, whose relationships were almost exclusively with either family members or professionals. On the other side, many of the relationships between professionals and people with ID were described as reciprocal, with several professionals showing close emotional commitments to the people they supported. There was an indication that adult services and key-professionals could take on the role of advocates and several participants spoke about social care services being able to offer people a 'sense of belonging'. Yet, inversely relationships between professionals and families were dependent on the wider service provision context, being vulnerable to changes in funding, recruitment and retainment of staff and re-structuring of services, placing relationships at risk to be suddenly cut-off and discontinue (Small et al., 2013). Relationships between people with ID and professionals are commonly portrayed as problematic, highlighting the unequal nature of relationships (Altermark, 2016). However, there are also more positive portrayals that describe staff maintaining relationships after they have left services and staff extending the social networks of people by inviting them into their social worlds (Forster and Iacono, 2008, Johnson et al., 2012, Newton et al., 1995). Across my three studies people considered if relationships with professionals could be positive, if they were indeed often similar to relationships between friends or family members, and if services could offer a sense of belonging.

7.2.1.1 There is more to caring than care

There is a closeness there that care just is not the right word. (Mia, social care professional, study three)

The Scottish government recently started a campaign to attract more people into careers in adult social care, which saw posters placed across Scottish cities, citing the slogan 'There is more to care than caring'. This reflects an understanding of caring as something quite ordinary, something that does not require skill, that is not professional. The emphasis seems to be placed on providing care **for**, rather than caring about. In a UK context social care is often described using professional language. Emphasising choice and personalisation, care relationships are portrayed to be between 'clients' and 'service providers' (Clarke, 2006, Glendinning, 2008). Such a consumerist view to social care stands in a stark contrast to the narratives of social care professionals across my three studies. In interviews participants spoke about their emotional ties to

people, highlighting the central role caring played in facilitating involvement and belonging. The experiences of participants were more closely connected to an understanding of care as relationship-based work, as it is defined in the tradition of Social Pedagogy, which is widely practiced in many mainland European countries (Hatton, 2013, Kirkwood et al., 2019). Social Pedagogy has been called a 'pedagogy of relationships' (Stephens, 2009). It describes how care-relationships take place in shared social spaces and acknowledges the emotional sphere of those relationships, recognising that the quality of relationships that professionals and people build over time, will have a significant influence on practice and outcomes (Stephens, 2009). The emotional sphere of caring has been emphasised by others. In his study Altermark (2016) found that support workers often referred to their relationships with the people they supported as friendships or being like family. Equally, Gaventa (2019) criticises models that are built on professional distance, stating that they are unable to perceive the complexity of human relationships. He argues that views of professional distance negate people with ID the right to be involved in defining care relationships. Thinking about the relationships I observed between people with severe ID and their carers, I recall how people related to their carers by looking for emotional and physical closeness, as well as clearly indicating when they wanted their own space. People were reaching out to hold hands, requesting hugs, laughing and smiling when songs were sung together, or meals were shared. I would like to stress that I do not want to ignore or disregard the power dynamics that are inherent within care relationships, particularly in relationships with people who are non-verbal. Rather, I believe that my findings emphasise how concepts of independence, professional distance and autonomy are unable to reflect the relationships experienced by people, including the person with severe ID.

7.2.1.2 Who will be there at the end?

The main worry parents had was who would care about their children and ensure their wellbeing once parents were no longer able to be involved. Interestingly, in cases where families and adult services had strong connections and worked closely together, families seemed to have less worries and have a more positive regard for the future. Particularly in study two and three adult services showed a commitment towards people and the ability to take on advocacy roles alongside families. Similarly, Ledger's (2012) study, which explored support networks that enabled people with ID and high

support needs to stay within their local areas, highlighted the central role that support services can play in advocating on behalf of people. She describes how services 'stuck' with people through difficulties and how 'staff allies', who had close personal knowledge of the individual, were able to advocate on their behalf and facilitate a sense of belonging to local areas (p. 382). Yet, thinking of the other side of the coin, all three of my studies simultaneously highlighted the fragility of existing support networks. There was an underlying anxiety that things could quickly change for people, and they could find themselves in places where no one would know them. It was difficult for services and individual professionals to promise that they would be able to stay with the person till the end, as they were dependent on receiving the necessary support and funding should the needs of the person change within older age.

7.2.1.3 Concluding remarks

Small et al. (2013) have noted that there seems to be little consideration to maintain or widen people's networks as part of transition planning. Similarly, many of the transitions across my studies were characterised by discontinuity of support networks. In study one and two, in all except Peter's case, transitions involved discussions about people losing existing networks, such as their day services or additional respite services, as they made the move to a new service. Additionally, an understanding of care as relational also emphasises the importance of having spaces where relationships can be built and exercised. Local authorities have largely moved away from providing support in group homes or day services, mirroring policy goals of inclusion and personalisation that decentralise support and locate it within the home or public spaces (Hall, 2010, Power, 2013). However, Power (2013) argues that the image of the inclusive mainstream society can be deceptive, as it omits that many of us seek shelter within smaller groups or 'bubbles' of like-minded people, as illustrated in recent research within social geography (Conradson, 2013, Philo and Metzel, 2005). Similarly, to the work of Hall (2010) and Power (2013), my findings show how specialist ID services and spaces can have value in offering people places where they can feel accepted, where they are known and where they can have valued social roles. Instead of concentrating on service models or policies my findings note the importance of focussing on the relationships people have in their lives and in how far the continuity of relationships and the development of new relationships is supported.

7.2.2 People's sense of belonging within wider systems

We are more in a corporate sort of world and environment and it is, if you are an old school social worker like me it is really not great (...) if you feel like you are fighting a system. (Emma's social worker, study one)

This section explores caring in relation to the socio-political sphere and organisational practices. There is now a growing awareness that values of care and kindness do not only belong within the personal realm, but that we should consider in how far there is room for kindness and care within the systems and structures that shape our lives (Rogers, 2016, Unwin, 2018). As the quote above illustrates, many professionals talked about how limitations within the systems and structures they worked in did not allow them to be person-centred or offer choice. During data collection I felt as if I met many caring professionals, who were working within a wider system that showed little care, not only for people with ID, but also for them. In Tom and Emma's case social workers talked about how some of their colleagues had recently left their team in a move to reduce costs, with the future of the transition social work team unsure. All local authority professionals spoke about reductions in cost, and the stress to meet increasing demands within the social care sector. Furthermore, across adult service providers there was an awareness of the difficulty to recruit and retain staff, due to difficult working hours and relatively low pay compared to the responsibilities involved. Unwin (2018) argues for the importance to include kindness as a core-value of public services. She describes how a strive for greater accountability and predictability has led to the development of a transactional, instead of a relational approach to public services. This approach sees social care as a service that is offered to dependent and vulnerable groups in society, funded by those who are independent and able. She notes how a focus on kindness within public services can have negative connotations, creating a picture of charity that is based on pity. Yet, echoing an ethics of care approach, she argues that if kindness is lifted into the socio-political sphere and understood as a core-value of public services, it can create solidarity and foster a sense of mutuality. Thus, she builds on the work of Brownlie and Anderson (2018) to differentiate between kindness, which is found in one-to-one relationships and radical kindness, which demands substantial institutional change. My data illustrated many instances of kindness in one-to-one relationships, which was exemplified by carers who went the extra mile. However, there was a lack of accountable systems and secure webs of support that people could count on should existing relationships

discontinue (Rogers, 2016). Unwin's (2018) call for radical change echoes Malleson's (2017) vision of transformational change as society awakens to the realisation of Interdependency. Unwin (2018) argues that we need turn to radical kindness to create a system that offers people better security. She states:

Public policy cannot continue to applaud the efforts of individuals and communities without recognising that these same efforts demand action that is different, and a new approach to power. (p. 38).

A statement that rings especially true as I am writing this chapter during the Coronavirus pandemic.

7.2.2.1 Concluding remarks

The question 'Who cares?' was central to the narratives of mothers in study one and two. In the quote at the beginning of this section we can see Emma's mother grappling with the interdependence of the private and public realm of care. She says, it doesn't matter to anyone else, it is no one else's fault, it is to a large extent our private journey as a family, but in a roundabout way it should matter to society, it has all to do with how society sees us and supports us (or not). I am writing this chapter at a time where there has been a lot of talk about finding 'a new normal', as humans across the world have found themselves in a position of great vulnerability. If we learn from this experience and understand the inherently interdependent and vulnerable nature of our lives, we might decide to follow authors who argue for the need to re-conceptualise states as caring states (Malleson, 2017, Rogers, 2016, Tronto, 1993). The argument of many ethics of care writers is that by recognising that we are all inherently vulnerable and dependent, that our vulnerability connects us to each other, we can move from seeing intellectual disability as a personal tragedy to creating a shared sense of solidarity that gives the right to adequate care and support a central place within society (Kittay, 2001, Malleson, 2017, Sevenhuijsen, 1998).

8. CONCLUSION

In this chapter I reflect on the strengths and limitations of my three studies, focusing on my experiences of involving people with severe ID in the research process. This will be followed by considering the implications of my research findings to policy and practice.

I believe that the central finding of my PhD is how important relationships are. Throughout my three studies it became apparent that good transitions, good support and good lives depend on the existence of caring and loving relationships. Relationships to attentive and supportive others enabled people with severe ID to be listened to, to be included in activities, to feel valued, accepted and loved. Additionally, taking an ecological perspective and including the experiences of multiple people involved demonstrated the importance of supportive relationships for families, as well as professionals. The amount and quality of support family members and professionals were able to provide to the person depended partly on how much they themselves felt listened to, supported and cared about. Thus, the lives of people with severe ID and those that care for and about them are interdependent. I believe that my data included a lot of positives in relation to practices and relationships within people's immediate environment, maybe giving a contrast to some of the more bleak accounts of the lives of adults with severe ID (Altermark, 2016, Bigby et al., 2009, Hubert, 1991, Hubert, 2011). However, my three studies also highlighted barriers, concerns and struggles of families, as well as professionals. Those were mainly located within people's interactions with wider levels, their experiences of scarce resources, inflexible organisational structures and a gap between the ideals of policies and actual possibilities within practice, resulting in a sense of helplessness and frustration. A life-course perspective illustrated continuities and discontinuities of relationships during transitions, highlighting the fragility of professional support networks and uncertainty about the reliability of their involvement in the lives of families. The central role of relationships also stood out in my experiences of trying to involve people with severe ID within my research. Thus, throughout the next two sections I will emphasise the importance of paying attention to the relationships that people have in their lives, building on them and if possible, strengthening them.

8.1 Strengths and limitations of my research – methodological conclusions

This section will include an examination of the strengths and limitations of my research. I begin by examining the trustworthiness of my studies, secondly I discuss the benefits of taking an ecological approach to data collection, thirdly I reflect on the limitations of the design of study three and limitations in relation to my recruitment across all three studies, and lastly I explore how successful I have been in involving people with severe ID within my research.

8.1.1 Trustworthiness

To assess the strength of qualitative research studies, authors suggest that we assess how trustworthy the provided account is, how confident we can be that there are links between the data and interpretations that have been made and how transparent the researcher has been about his or her own role in the interpretative process (Connelly, 2016, Lincoln and Guba, 1986, McGloin, 2008). This thesis provides an account of transitions that has been written by me and is influenced by what I decided to include and exclude. Additionally, my findings are not only inherently linked to my own perspective and interpretations but likewise to the perspectives of participants. During interviews participants shared their experiences from their own perspectives, making decisions what they were willing to share with me at that moment in time and certain aspects, experiences and events might have been missed. Furthermore, although I explored transition through the use of different data sources there was information I was not able to access and perspectives that are missing. Thus, while I can't claim that my account of the transition processes are a complete and objective representation, I hope that I have been transparent about my actions and choices throughout this thesis. I have provided extended sequences of my data to ensure my interpretations are grounded within it and I have involved participants in validating my view of what they shared with me.

8.1.1.1 Transparency

Transparency has been very important to me throughout my research. Ledger (2012) describes how inclusive and accessible research should also include telling the story of conducting the research project. Thus, by combining detailed descriptions from my

fieldnotes, extracts from interviews and my observations I hope that I was able to include the story of how I conducted my research within the story of each transition journey. Few approaches to data analysis include the researcher's experiences within the write-up. Choosing a narrative approach to present each case allowed me to include my own experiences and views, which aided a more transparent reflection of the research process. Additionally, a narrative approach enabled me to illustrate the different perspectives and roles of my participants. The crafted descriptions of each transition process are written by me and reflect my own standpoint as the researcher but by using large sections from my observations and interviews with participants, the participants themselves also became more visible.

8.1.1.2 Involving participants in the validation of my findings

I was able to discuss my transition timelines with all mothers and one professional in each of the six cases in study one and two. Furthermore, each participant across all studies received a summary of our interview, as well as a summary of findings of the whole study once it was completed. Out of 42 participants, 22 responded to the interview summaries, and 18 agreed that my interpretations reflected their experiences. Four participants asked to have certain passages changed to clarify what they had wanted to say or to add additional information. Getting feedback from participants on my interpretations was immensely helpful and particular the four requests for changes highlight the importance of providing participants with summaries of research findings.

8.1.2 The benefits of an ecological approach to data collection

The use of an ecological model across my three studies helped me to illustrate the multiple layers and networks involved in decision-making processes at times of transitions. My three studies highlight how difficulties experienced by families are inherently linked to organisational practices, material resources, as well as cultural understandings of what a good life is or what adulthood means. At the same time, I was able to include an account of people's impairment and its impact on their and their families' lives. This enabled me to highlight the importance of access to specialist equipment or services, such as speech and language or mental health services, to support people's development and wellbeing. Thus, my study contributes to an

understanding of transitions and disability as multi-dimensional (Jindal-Snape, 2016, Jindal-Snape et al., 2019a, Jindal-Snape et al., 2019b, Bhaskar and Danermark, 2006).

8.1.3 Limitations

Study three differed in its design from study one and two, as I was only able to conduct interviews with social care professionals. Combining the perspectives of social care professionals with experiences of families, social workers and health professionals could provide a deeper and more multi-faceted account of transitions in old age. Additionally, it would have been an advantage to combine my interviews with observations of professionals interacting with the people they support. Participants reflecting on and talking about their work experiences in interviews does not necessarily describe how they act in practice and researchers should be cautious about inferring from one to the other (Broadhurst and Mason, 2014, Ferguson, 2014).

Overall, my three studies included many positive descriptions of the relationships between people, families, services and professionals. Parents in study one and two were all proactive and able to advocate on behalf of their children. While all six adults were able to access services that were appropriate and appeared to be able to meet their needs, there was an awareness across cases that this was not a reality for all families. I had initially hoped to be able to include cases of families who were experiencing greater conflict but through conversations with the recruitment organisations I realised that families whose transition experiences were more complex and where communication with local authorities was breaking down understandably felt unable to speak to me. While I have argued previously in my methods chapter that the aim of my research is not to generalise, it is still important to keep in mind that the experiences of people in this research do not reflect the range of experiences that other families and adults with severe ID will have. My sampling strategy might have added to the bias of recruiting families whose experiences were more positive. My aim to speak to professionals might have alienated parents experiencing conflict with those professionals. Additionally, families in the midst of difficult transition processes most likely felt less able to commit additional time to take part in my research. A research design that enables researchers to build stronger and longer relationships to families, might be more suitable to include families that experience greater stress and conflict.

This could be achieved by an ethnographic design, where the researcher is based at a school or adult service. By becoming part of a setting, researchers can get to know families and professionals and build relationships over a longer time frame (Mietola et al, 2017). Furthermore, such a design might facilitate a stronger involvement of perspectives that were difficult for me to access, including the views of fathers, siblings and social workers.

Tensions between the right of participants to anonymity, and the benefit of rich, contextual information is well documented in relation to qualitative research (Jindal-Snape, 2016, Tilley and Woodthorpe, 2011). Being more awake to the ethical complexity of balancing both could have helped me to explore in more depth with participants how comfortable they might have felt with me sharing more detailed information. As I missed the opportunity to explore the inclusion of contextual information with participants as part of the consent process, I found myself in the situation of needing to exclude some of my data to uphold participants' right to anonymity and confidentiality. This leads to gaps in my data. While I was able to portray transition processes in detail, I have been unable to at times embed them in the wider context they occur in. For example, the unique environment of both settings in study three influenced the findings. Naming both settings and providing more detailed information about their organisational culture could have helped readers to understand why my findings were different to other studies that have been conducted in this area. Furthermore, naming local authorities could have helped me to explore the impact of different policies and differences in access to resources in local areas, while more detailed information about each family could have helped to further understand differences in the involvement of siblings or in how far economic circumstances or ages of parents impacted on their experiences.

8.1.4 Involvement of people with severe ID within my research

One of the central aims of my study was to give greater visibility to people with severe ID in research. I quickly recognised parallels of wanting to include people within the research process and focusing on how people with severe ID are involved in transition processes as the topic of my research. Thus, many of the points I make here will be relevant again later on when I consider in how far my findings can add to a stronger involvement of people in transition processes.

The attempt to include an account of people's lives and experiences relied on the accounts of others, focusing on people in interviews with those that knew them well, accessing personal plans and spending time with them during my observations. Spending time with the six adults helped me to connect interviews and documents to the actual human being at the centre of each process. It was different to spend time with people than only hearing parents and professionals talk about them. For example, Emma being described as enjoying busy and industrious environments was clearly visible for me when I saw her preparing vegetables with others and signing with peers and staff, and I experienced the hardship and difficulties that were present in interviews in Tom's case around his self-injurious behaviour in my own difficulties of seeing him in distress. Additionally, similarly to (Davis et al., 2000), Oulton et al, (2017) and Mietola et al (2017), my observations helped me to see how each person showed agency and was making choices through their behaviour within their immediate environment such as expressing emotions, leaving an activity, approaching staff members and choosing when to be active and when to rest. Thus, my observations gave me the opportunity to see people '*as competent social actors who may make decisions about whether to communicate and with whom, being 'the final gatekeepers to their worlds'.*' (Davis et al., 2000, p.210, as cited in Nind, 2008, p. 14).

When I initially planned my research, I was worried about involving people with severe ID, worried about getting ethical approval for study one and two and I was anxious that my observations could cause the person distress. Looking back, I was maybe too apprehensive and based on what I know now I would make the observations a more central part of my research. My experiences of meeting people and conducting the observations were very positive and I believe that my observations and reflections on meeting each person are an integral part of my data. Additionally, conducting interviews with several people who knew the person helped me to recognise that the six adults were different in different environments and had formed distinctive relationships with different people. Thus, similarly to Simmons and Watson (2014), including multiple perspectives helped me to form a deeper and more complex understanding of each person. Having a longer-term involvement with each person

and spending time with them in different environments would have been helpful to explore their relationships to different settings and people even further.

As I stated in the introduction to my thesis, my aim is not 'to give voice' to people with severe ID. I believe that people with severe ID communicate their feelings, likes and preferences, albeit in different ways. Conducting this research has shown me that barriers to involving people with severe ID in research have a lot to do with the way that we conceptualise involvement. In his article on the sociocultural study of intellectual disability, Klotz (2004) explores in how far the lives of people with severe ID have been included in research over past decades. He uses the work of Edgerton as an example to illustrate how dominant socially prescribed norms that view people as autonomous, verbal and rational human beings, have led to the exclusion of people with severe ID from research. He describes how Edgerton's ethnographic studies of the lives of people with ID inside institutions at first also included accounts of people with severe ID. In their paper 'On the possibility of friendship' MacAndrew and Edgerton (1966) provide an endearing description of meaningful interactions between two young men with profound ID. However, when he turned to explore deinstitutionalisation and the move towards care in the community, Edgerton's work started to focus on people with mild and moderate ID). Edgerton felt that it was difficult to conceptualise how adults with severe ID could be included in the move to community living (Edgerton, 1967, pp. 2-3, as cited in Klotz, 2001), while also reflecting that differences in their ability to communicate made it more difficult to involve people with severe ID in research (MacAndrew and Edgerton, 1970). I believe that this example illustrates that the exclusion of people with severe ID in research originates from the dominant view that meaningful research engagement and interactions takes place between rational and verbal human beings. Yet, this view is based on an abstract ideal, instead of everyday life experiences. I believe that when we go and meet people with severe ID, when we take an interest and take the time to 'listen', it becomes quite clear that they are able to have meaningful interactions with others and communicate their feelings and preferences. The work of MacAndrew and Edgerton (1966) 'On the possibility of friendship' is one example of this. I believe that it is essential that we reflect on our own assumptions of how research involvement looks like and that we are brave to embrace difference and explore different ways of involving people whose

communication is inherently bound to their immediate environments. I agree with Mietola et al. (2017) and Klotz (2004) that drawing on ethnographic research is a promising approach to facilitate the involvement and visibility of people with severe ID in future studies. This will not only help to produce research findings that are more relevant, I believe that it will also help us to affirm their human status and personhood.

8.2 Implications of findings to policy and practice

Building on my discussion, in this section I propose that interdependence should be the ideology that underlies policy and practice. My studies support the findings of others that care relationships, as well as relationships between families and institutions, are characterised by interdependence (Pilnick et al., 2011, Rogers, 2016, Ryan, 2020, Small et al., 2013, Nind and Strnadová, 2020). Additionally, understanding involvement through the lens of interdependence allowed participants to recognise the agency people with severe ID have within their relationships, instead of seeing them as passive and merely dependent. As I have argued within the discussion chapter, interdependence as an ideology allows us to bridge divides between policy and practice and the findings of my PhD add to a growing awareness that the concept of interdependence might be more suitable to understand the lives of people with ID (Malleson, 2017, Pilnick et al., 2011, Porter, 2006).

Taking interdependence seriously has several implications to policy and practice. In the following I will discuss those implications in relation to (i) the involvement of people with severe ID in transitions and the role of advocacy, (ii) the need to re-define concepts such as choice and independence and (iii) the importance to consider people's relationships as part of transition planning.

8.2.1 Reconceptualising involvement – the importance of everyday knowledge and advocacy

The CRPD (2006) promotes participation of persons with disabilities in all matters including policymaking and service commissioning. Across my three studies there was evidence that people were involved in their immediate environment. This was apparent in people directly requesting certain activities such as listening to music or watching a movie through the use of words or their picture exchange communication books in the

present moment. This type of participation has been shown to be the most common one for people with severe ID, and researchers have argued that the participation of people often stops at the Microlevel (Talman et al, 2019). I believe that my findings go further and show how people were also involved in the planning of routines and activities if we understand involvement from a relational perspective, which gives space to consider advocacy as a way to facilitate involvement (Kruithof et al., 2020). Families and professionals made decisions about people's programs and suitability of services based on knowing about their preferences and by continuously observing their responses and behaviours in different environments. Yet, taking a relational view to understand involvement also highlighted tensions inherent in an approach that relies on interpretation and inferences. Close collaborative practice between those that knew the person well helped stakeholders to successfully support the person during the practical part of the transition. Yet, such collaborative practice was less apparent within wider levels. Involving those that have knowledge about the everyday lives of the person within wider decision-making processes could help us move the person from the Micro into the Exosystem and to start with the person rather than with what is available (Small et al, 2013, Ledger, 2012). Thus, my findings highlight the importance of advocacy to involve people with severe ID in wider decision-making and for local authorities to work with and listen to family members and frontline staff when planning transitions (Ryan, 2020). Involving families in the process of service commissioning appears particularly crucial to explore what meaningful services can look like. Detailed knowledge about everyday life experiences have been suggested by others as a way to facilitate participation of excluded groups within policy making and service commissioning and to bridge the gap between policy and practice (Löve et al., 2017, Smith, 1990). To facilitate an involvement that is based on detailed knowledge of people's everyday life experiences requires time (Ward and Stewart, 2008) and my findings echo best practice guidelines that recommend that transition planning should take place over several years (Scottish Transitions Forum, 2017). Yet, my findings further highlight that it is important to specify what transition planning entails to avoid that families who are looking for practical advice and support feel left alone, as transitions remain an abstract point on the review meeting agenda until a year or several month before the actual move.

8.2.2 Interdependence – the real normal

Concepts such as choice and independence can be complex to apply in practice. They evoke ideologies of autonomous human beings and in the context of severe ID professionals can feel unable to relate to them. In combination with decreasing resources they can be used to justify a decrease in support (less support = greater independence) or used to shift responsibility to families and individuals (it is your choice) (Pearson et al., 2020). Interdependence on the other hand emphasises the importance of social networks and resources to support people throughout their lives. Thus, interdependence helps us to make a clear connection between choice, independence and access to adequate support and resources. Additionally, interdependence as a concept allows for the possibility that the needs of adults' change, acknowledging that there might be times when a person will start to need more support to be included and engaged in local communities, and that some will always need a high level of support.

Interdependence and ethics of care stress the importance of moving care from the personal realm into the political. This moves the responsibility of providing care from families to the state. A state that is built on interdependence, would be a state that ensures that everyone has access to the support they need, increasing public resources to fund care (Malleon, 2017). It would also be a state that values those that work in caring professions. We often find a kind of romanticism of the caring professions, more recently with health and social care staff being called heroes and people clapping for them on the streets. However, while we are aware that the quality of frontline staff, such as care workers, is a crucial contributor to good health and social care services, social care continues to be an undervalued profession (Hayes and Moore, 2017, Lewis and West, 2014, Becker, 2020). A 'caring state' (Tronto, 2013) would change this and ensure that people in caring professions have improved working conditions, are well trained and well paid (Malleon, 2017).

8.2.3 Relationships matter!

It is the relationships we have to people that facilitate our engagement and experiences of the world. Recognising this would mean that there has to be a stronger emphasis on relationships and people's support networks in transition planning. My three studies showed that people often had close relationships to professionals.

Finding ways for those relationships to continue could help people to make the transition to a new and unknown environment. A longer overlap of networks during the transition process would allow those that know the person well to pass on their knowledge and for the person to slowly build new relationship. Loss of knowledge about the person and their way of expressing themselves is a concern during transitions (Middleton and Hewitt, 1999). This was exemplified by the case of Martin in study three. His parents were not alive any longer and his siblings lived far away when he made the transition into a nursing home. People from the community where he had lived for many years visited him regularly but felt that staff at the nursing home did not have a sense of who Martin was, that his identity had not moved with him, and he died shortly after his move. As Small et al. (2013) point out, people with ID are particularly vulnerable during transitions, when relationships discontinue, because of the '*deep but narrow range of support they experience*' (p. 286). At times of transition it seems paramount that people are able to maintain relationships so that we can build bridges between settings and places to ensure that people are known, so that they can be listened to, cared for and cared about.

I am writing this conclusion on the day that the new report on restraint, seclusion and segregation in care services for people with autism and/or learning disabilities in England has been published (Care Quality Commission, 2020). The report describes how too many people and their families are let down by the current system, detailing inhumane practices of segregation and restraint. Rogers (2016) reminds us that there are children and adults with ID who find themselves in spaces without caring relationships, whether that is in locked wards, supported living services or hospitals. The fear of their children suddenly finding themselves in spaces, without people they know and people who know them, was expressed by all families, as well as several professionals across my studies. A fear that stood in contrast to the positive accounts of people's current lives. The report of today and reports from previous years (Lenehan, 2017, MacDonald, 2018, Mental Welfare Commission, 2016b, Bubb, 2014) show that this fear is not unfounded and stems from an awareness that many adult health and social care services don't get it right and too many young people and adults are currently in places where they are isolated and their human rights are not met. So maybe it is not the time for further research but the time to finally act and transform and properly invest in adult social care.

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APPENDICES

Appendix 1: Ethics approval letters

NHS Ethics approval letter study one

Scotland A Research Ethics Committee

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
www.hra.nhs.uk



Scotland A REC
2nd Floor Waverley Gate
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08 March 2017

Ms Paula Charlotta Jacobs
University of Edinburgh
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
Edinburgh, EH8 9AG

Dear Ms Jacobs,

Study title:	A holistic understanding of decision-making for and with people with profound intellectual disabilities at times of transitioning into adulthood: A Multiple Case Study
REC reference:	17/SS/0002
IRAS project ID:	219851

Thank you for your letter of 08 February 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.r4forum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [cover letter]	1	17 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance documentation]	1	30 November 2016
GP/consultant information sheets or letters [Letter to GP]	1	29 November 2016
Interview schedules or topic guides for participants [Interview guide]	1	27 November 2016
IRAS Checklist XML [Checklist_17022017]		17 February 2017
Letters of invitation to participant [Initial letter]	1	27 November 2016
Other [insurance documentation]	1	30 November 2016
Other [Clinical Trial Liability]	1	30 November 2016
Other [Professional Indemnity]	1	30 November 2016
Other [second supervisor CV]	1	29 November 2016
Other [research protocol tracked]	2	02 February 2017
Participant information sheet (PIS) [Risk assessment]	1	28 November 2016
Participant information sheet (PIS) [PISCF parents as participants]	2	23 December 2016
Participant information sheet (PIS) [PISCF professionals]	1	29 November 2016
Participant information sheet (PIS) [PISCF Guardian]	2	23 December 2016
Participant information sheet (PIS) [PISCF family unit]	3	02 February 2017
Participant information sheet (PIS) [PISCF family unit tracked]	3	02 February 2017
Participant information sheet (PIS) [PISCF professionals]	2	02 February 2017
Participant information sheet (PIS) [PISCF professionals tracked]	2	02 February 2017
Participant information sheet (PIS) [PISCF other family members]	2	02 February 2017
Participant information sheet (PIS) [PISCF other family members tracked]	2	02 February 2017

Participant information sheet (PIS) [Risk assessment clean]	2	06 February 2017
Participant information sheet (PIS) [Risk assessment tracked]	2	06 February 2017
REC Application Form [REC_Form_06012017]		06 January 2017
Research protocol or project proposal [research protocol]	2	02 February 2017
Summary CV for Chief Investigator (CI) [student CV]	1	29 November 2016
Summary CV for supervisor (student research) [supervisor CV]	1	29 November 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

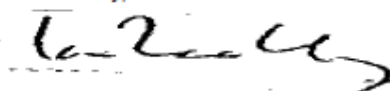
We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

17/SS/0002	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,



Dr Ian Zealley
Chair

Email: chloe.eves@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Miss Charlotte Smith, University of Edinburgh*

Scotland A Research Ethics Committee

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03 April 2017

Ms Paula Charlotta Jacobs
PhD student
University of Edinburgh
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
EH8 9AG

Dear Ms Jacobs

Study title: A holistic understanding of decision-making for and with people with profound intellectual disabilities at times of transitioning into adulthood: A Multiple Case Study
REC reference: 17/SS/0002
Amendment number: REC Ref 17/SS/0002/AM01
Amendment date: 21 March 2017
IRAS project ID: 219851

The above amendment was reviewed on 24 March 2017 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Committee had no ethical concerns regarding this SSA exemption request.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)		
Other [SSA Exemption Request]		

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/SS/0002:	Please quote this number on all correspondence

Yours sincerely,



Dr Colin Selby
Chair

E-mail: chloe.eves@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Charlotte Smith, University of Edinburgh*

NHS R&D approval letter study one

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

DY/CF/approval

27 June 2017

Ms Paula Jacobs
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
Edinburgh
EH8 9AG

Research & Development
Room E1.16
Tel: 0131 242 3330

Email:
accord@nhslothian.scot.nhs.uk

Director: Professor Tim Walsh



Dear Ms Jacobs

Lothian R&D Project No: 2017/0169

REC No: 17/SS/0002

Title of Research: A holistic understanding of decision-making for and with people with profound intellectual disabilities at times of transitioning into adulthood: A Multiple Case Study

Participant Information Sheet:

Version 2.0, dated 2 February 2017 (Professionals)

Consent Form:

Version 2.0, dated 2 February 2017 (Professionals)

Protocol: Version 2.0, dated 2 February 2017

I am pleased to inform you this letter provides Site Specific approval for NHS Lothian for the above study and you may proceed with your research, subject to the conditions below.

We advise that you contact any relevant NHS Practices where you may conduct the Health Professionals interviews to ensure you have the appropriate approvals in place for use of the premises.

Please note that the NHS Lothian R&D Office must be informed of any changes to the study such as amendments to the protocol, funding, recruitment, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please keep this office informed of the following study information:

1. Date you are ready to begin recruitment, date of the recruitment of the first participant and the monthly recruitment figures thereafter.
2. Date the final participant is recruited and the final recruitment figures.
3. Date your study / trial is completed within NHS Lothian.

I wish you every success with your study.

Yours sincerely


Dr Douglas Young
Principal R&D Manager

NHS approval letter subject to conditions being met study two

Scotland A Research Ethics Committee

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
www.hra.nhs.uk



Scotland A REC
2nd Floor Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5680

08 Feb 2018

MS Paula Charlotta Jacobs
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
EH8 9AG

Dear MS Jacobs

Study title:	Transitions for and with adults with severe or profound intellectual disabilities within adult services: A Multiple Case Study
REC reference:	18/SS/0005
Protocol number:	CAHSS1712/02
IRAS project ID:	240297

The Research Ethics Committee reviewed the above application at the meeting held on 25 January 2018. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Additional conditions:

The Participant Information Sheet – (and protocol as applicable) should be revised as follows:

1. Submit the PIS and Consent Form as two separate documents
2. A shortened PIS for Relatives & Family /Friends is recommended
3. The sentence at A35 on the IRAS form, referring to destroying data if the participants lost capacity is to be removed.

General (amend protocol if applicable):-

4. Identify types of transitions in the inclusion/exclusion criteria
5. Clarify the storage of photos giving a time limit of when they will be destroyed after the study
6. Remove the GP letter

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Summary of discussion at the meeting

Ethical issues, noted and resolved in preliminary discussion

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The committee considered this a low risk study.

Suitability of the applicant and supporting staff

No issues were raised

Independent review

No issues were raised

Suitability of supporting information

No issues were raised

Other general comments

No issues were raised

Suitability of the summary of the research

This was confirmed

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting

The Chair welcomed Paula Jacobs (CI and Student) and Dr Ethel Quayle to the meeting. The Chair informed the researchers that there was an observer in attendance at the meeting and that they could request that the observers be asked to leave if they wished to do so. The researchers confirmed that they had no objection to the observers being present

Social or scientific value; scientific design and conduct of the study

The Committee noted that this study is a follow on study to one which used the same methodology known as reflective bracketing. This design had been reviewed and approved by the university. The Committee queried the attribution as a "multiple case study design" when they have stated that there may be 1-3 adults followed through the transition process.

The Researchers answered that three would be the optimum number they were trying to achieve, however they may only get one in which case they would change the title

The Committee asked for clarification of the selection process for candidates as there may be bias if it was based on those participants who had volunteered and whether there was a filter as to what stage they would be brought to the attention of the research group.

The Researcher explained that recruitment would be through two small organisations which support families. Both these groups would be sent letters and they would then identify the families and young people.

The Committee suggested that there might be a clear inclusion exclusion criteria which specified that the participants would be at are in transition and they type of transition.

The Researcher clarified that this has been specified and it would be documented at which stage the participants were in.

The Committee suggested that examples of the cases which the researchers would like to see i.e. clarify that the aim is to study a range of transitions.

The Researcher replied that the organisations they are recruiting from are different so a different range would be expected.

The Committee considered this suitable, however did not think that the GP letter was necessary and suggested that particularly with the carer input, it would be the social work department which would benefit from information as this study is looking at a process.

Recruitment arrangements and access to health information, and fair participant selection

Additionally the committee queried whether the recruitment was phased or overlapping as it was recommended that recruitment should be phased.

The Researcher confirmed that the planned recruitment was overlapping

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee were concerned about the "photograph" part of the study and asked for an explanation of what photos were taken, how they would be anonymised and what the plan and time limit for destruction was.

The Researcher explained that the photos were part of the data collection if they include observations. These would be sharing of a picture of an art picture the participant had created which did not need anonymised. The photos of people would be stored safely with the photos of artefacts in the encrypted laptop but will not be used in the final analysis

Informed consent process and the adequacy and completeness of participant information

The Committee noted that there was a sentence in A35 on the IRAS form referring to destroying data if the participants lost capacity which was quite confusing as all the participants were AWI.

The Committee are of the opinion that this needs to be changed.

The Committee commented that the PIS for the family unit (Family members and friends), was quite long and that a shortened version of the PIS of approximately one side of A4 paper, would be beneficial.

The Researcher agreed

The Committee noted that although the PIS was for a relative, it consistently referred to "your son/daughter" and explained that they would like clarification, as to whether this PIS was only referring to biological offspring.

The Researcher explained that this was the first study to include foster parents and agreed that the wording in the PIS should not only refer to "sons and daughter" as it was not restricted to biological parents.

The Committee asked the researcher why there were two consent forms, as it was the Legal/Welfare guardian who would give consent for the participant.

The Researcher explained that there are two consent forms for the family unit, although it is only the legal guardian/family who gives consent for the participant; the members of the family unit need their own consent forms for participating.

The Committee also suggested that each PIS and Consent form should be presented as two separate documents

The Researcher agreed

Adults with Incapacity

The Committee agreed that in order to answer the principal research question, the research required the inclusion of adults with incapacity, as it was a study of participants with profound learning disabilities.

The Committee agreed that although there may be no real and direct benefit to the adults involved, it would be of benefit to others with the same condition.

The Committee agreed that there was no foreseeable risk/discomfort or only minimal risk/discomfort for the participants.

The Committee agreed that appropriate arrangements have been made to obtain consent from a legal representative (guardian, welfare attorney, or if neither have been appointed, the nearest relative).

The Committee noted the waiver for an SSA request and agreed to this waiver

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
GP/consultant information sheets or letters [Letter to GP]	1	04 December 2017
Interview schedules or topic guides for participants [interview guide]	1	04 December 2017
IRAS Application Form [IRAS_Form_21122017]		21 December 2017
Letters of invitation to participant [initial letter to organisations]	1	04 December 2017
Other [Clinical Trial liability Insurance]		
Other [risk assessment]	1	04 December 2017
Other [second supervisor CV]	1	05 December 2017
Other [declaration by chief investigator]	1	11 December 2017
Other [public liability confirmation]		
Other [PI confirmation]		
Other [employers liability certificate]		
Other [SSA exemption]		
Participant information sheet (PIS) [PISCF family unit]	1	04 December 2017
Participant information sheet (PIS) [PISCF professionals]	1	04 December 2017
Participant information sheet (PIS) [PISCF family members and friends]	1	04 December 2017
Research protocol or project proposal [Research Protocol]	1	04 December 2017
Summary CV for Chief Investigator (CI) [CV main researcher]	1	04 December 2017
Summary CV for supervisor (student research) [supervisor CV]	1	04 December 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

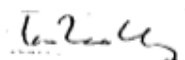
<http://www.hra.nhs.uk/hra-training/>

18/SS/0005

<i>Please quote this number on all correspondence</i>

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Ian Zealley
Chair

E-mail: ianx.neill@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting*

NHS approval letter after review of submitted changes study two



Scotland A Research Ethics Committee

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5680
www.hra.nhs.uk

Enquiries to: Manx Neill
Extension: 35680
Direct Line: 0131 465 5680
Email: manx.neill@nhslothian.scot.nhs.uk

05 March 2018

MS Paula Charlotta Jacobs
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
EH8 9AG

Dear MS Jacobs,

Study title: Transitions for and with adults with severe or profound intellectual disabilities within adult services: A Multiple Case Study
REC reference: 18/SS/0005
Protocol number: CAHSS1712/02
IRAS project ID: 240297

Thank you for your letter. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 08 February 2018

Documents received

The documents received were as follows:

Document	Version	Date
Response to Additional Conditions Met [Short PIS-Family Unit-Clean]	V3	01 March 2018
Response to Additional Conditions Met [Short PIS-Family Unit-TC]	V3	01 March 2018
Response to Additional Conditions Met [Short PIS-Family Members & Friends-Clean]	V3	01 March 2018
Response to Additional Conditions Met [Short PIS-Family Members & Friends-TC]	V3	01 March 2018
Response to Additional Conditions Met [Short PIS-Professionals-Clean]	V3	01 March 2018

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Response to Additional Conditions Met [Short PIS-Professionals-TC]	V3	01 March 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering letter on headed paper		
Interview schedules or topic guides for participants [interview guide]	1	04 December 2017
IRAS Application Form [IRAS_Form_21122017]		21 December 2017
IRAS Checklist XML [Checklist_05032018]		05 March 2018
Letters of invitation to participant [initial letter to organisations]	1	04 December 2017
Other [Clinical Trial liability Insurance]		
Other [risk assessment]	1	04 December 2017
Other [second supervisor CV]	1	05 December 2017
Other [declaration by chief investigator]	1	11 December 2017
Other [public liability confirmation]		
Other [PI confirmation]		
Other [employers liability certificate]		
Other [SSA exemption]		
Other [research protocol tracked]	2	12 February 2018
Participant consent form [consent form (parents or guardians)]	2	09 February 2018
Participant consent form [nearest relative consent form]	2	09 February 2018
Participant consent form [consent form family friends]	2	09 February 2018
Participant consent form [consent form professionals]	2	13 February 2018
Participant information sheet (PIS) [PISCF family members and friends]	1	04 December 2017
Participant information sheet (PIS) [PIS family unit clean]	2	13 February 2018
Participant information sheet (PIS) [PIS family unit tracked]	2	13 February 2018
Participant information sheet (PIS) [PIS family members and friends clean]	2	13 February 2018
Participant information sheet (PIS) [PIS family members	2	13 February

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

and friends tracked]		2018
Participant information sheet (PIS) [PIS professionals clean]	2	13 February 2018
Participant information sheet (PIS) [PIS professionals tracked]	2	13 February 2018
Participant information sheet (PIS) [PIS family unit]	3	01 March 2018
Participant information sheet (PIS) [PIS family members and friends]	3	01 March 2018
Participant information sheet (PIS) [PIS family unit tracked]	3	01 March 2018
Participant information sheet (PIS) [PIS family members and friends tracked]	3	01 March 2018
Participant information sheet (PIS) [PIS professionals]	3	01 March 2018
Participant information sheet (PIS) [PIS professionals tracked]	3	01 March 2018
Research protocol or project proposal [research protocol clean]	2	12 February 2018
Short PIS-Family Unit-Clean	V3	01 March 2018
Short PIS-Family Unit-TC	V3	01 March 2018
Short PIS-Family Members & Friends-Clean	V3	01 March 2018
Short PIS-Family Members & Friends-TC	V3	01 March 2018
Short PIS-Professionals-Clean	V3	01 March 2018
Short PIS-Professionals-TC	V3	01 March 2018
Summary CV for Chief Investigator (CI) [CV main researcher]	1	04 December 2017
Summary CV for supervisor (student research) [supervisor CV]	1	04 December 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

18/SS/0005	Please quote this number on all correspondence

Yours sincerely



Manx Neill
SAREC Manager

E-mail: manx.neill@nhslothian.scot.nhs.uk

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

University of Edinburgh ethics approval letter study three



SCHOOL OF HEALTH IN SOCIAL SCIENCE
CLINICAL AND HEALTH PSYCHOLOGY

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

Paula Jacobs
PhD Student
School of Health in Social Science
University of Edinburgh

10 April 2018

Dear Paula,

Application for Level 1 Ethical Approval

Reference: CLIN472

Project Title: Transitions into older age for adults with intellectual disability and severe communication difficulties: An exploration of professionals' views

Academic Supervisor(s): Ken MacMahon / Ethel Quayle

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 9th April 2018.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K. Gardner'.

Kirsty Gardner
Administrative Secretary, Clinical Psychology

Appendix 2: Examples of Participant Information Sheets (PIS) and Consent Forms

PIS study two: The family unit as participants

Transitions in adulthood for people with severe or profound intellectual disabilities
PIS (The family unit as participants), version no. [3], date [01/03/2018]



[Paula Jacobs,
School of Health in Social Science
Medical School (Doorway 6)
Teviot Place
EH8 9AG Edinburgh,
07957 281207
s1368461@sms.ed.ac.uk]

Participant Information Sheet

Transitions in adulthood for people with severe or profound intellectual disabilities

You and your relative are being invited to take part in a research study. Before you decide whether or not to take part and whether or not your relative should take part, please take time to read the following information carefully.

What is the purpose of the study?

The proposed study aims to look at how decisions are made for and with adults with severe or profound intellectual disabilities (ID) at times of transitions within adult services. This might be (1) a transition from one adult service to another, (2) transitioning out of the family home or (3) cases where it is felt that a change would be important and where a transition is wanted but where there might be nowhere to transition to. The study is interested to explore how transition processes could be improved, what works well and what does not.

Why have we been asked to take part?

You have been asked to take part, as you are the parent/guardian of an adult with severe or profound ID who is approaching or has recently experienced a transition within adult services. Your [son/daughter] lacks the capacity to make an informed decision about whether they can take part in the research study. We are therefore asking you as their nearest relative, welfare attorney or guardian if you will give consent on their behalf to join this study as well as giving consent on taking part yourself.

What will we have to do?

The researcher would like to interview you and others who are involved in the transition and your [son/daughter's] life. Those might be other family members, friends, staff at adult services and professionals such as Social Workers. Once you have had an initial meeting with the researcher she will try and approach anyone else you think will be valuable to talk to. The researcher hopes to do at least one initial and one follow up interview to talk about your views and experiences (around 60 min). Interviews will be recorded on a digital recorder, so the researcher can transcribe them and you are free to decide what you would like to share.

Additionally, the researcher would like look at specific documents that hold relevant information about the transition process (personal plans, meeting notes). Some of the documents will be third party documents and there may be restrictions placed on the researcher about how she can use them.

The researcher might also meet and observe your [son/daughter] to get a better understanding of the person at the center of the process if you feel this will be appropriate and not cause him/her any distress. If you would not like your [son/daughter] to be directly involved, then this won't be necessary.

Do we have to take part?

No, it is up to you to decide whether or not to take part. You are free to withdraw your consent at any time and without giving a reason. However, if you withdraw your consent

once the research has been completed we would use the anonymised content of information. If you take part in the research or not will not impact on the level of support you or your [son/daughter] will receive during the transition process.

What are the possible benefits and disadvantaged of taking part?

We hope that you feel this is a valuable area of research. The project provides the opportunity to share your and your [son/daughter's] experiences and your views on the transition process.

If you feel that conducting the research will cause your [son/daughter] any distress or feel intrusive then we think it is better not to participate in the study. Given the nature of the topic area, there is a possibility that some people may become upset. Support groups are available, details of which are given below.

PAMIS Family support service: contact information on <http://pamis.org.uk/about/local-branches/>

The Challenging Behaviour Foundation: Practical information and emotional support: 0300 666 0126

Will my taking part in the study be kept confidential?

Yes, all the information we collect during the course of the research will be kept confidential and stored securely. The only exception would be if you tell the researcher that a vulnerable adult is at risk, or that you have concerns about standard of care. If that happened, the researcher would follow standard adult protection procedures.

All personal identifiable information will be removed from documents, observations and interview transcripts. The transcripts of the interviews, discussions, observation notes and copies of documents **once all personally identifiable information is removed**, will be stored at Edinburgh University long-term secure storage. This will be held for 5 years.

What will happen to the results of the study?

The study will be written up as a thesis, for a PhD and findings in the research could be communicated to a wider audience..

If you would like then a summary of the research project will be sent to you.

Who is organising the research?

This study is being organised by Edinburgh University. The researchers name is Paula Jacobs and her supervisor is Dr Ken MacMahon (Senior Lecturer/ Clinical Psychologist). He can be contacted on: 0131 651 3960 or ken.macmahon@ed.ac.uk

If you would like to discuss the study with someone independent of the study please contact Dr. Angus MacBeth on: 0131 651 3960 or angus.macbeth@ed.ac.uk and if you wish to make a complaint about the study please contact the University of Edinburgh's Research Governance team via email at: resgov@accord.scot

Scotland A Research Ethics Committee and the School of Health in Social Science ethics committee have reviewed the study proposal.

How do I take part?

Please contact the researcher, Paula Jacobs, on: 07957 281207 or email: s1368461@sms.ed.ac.uk. She will arrange a time and place to meet with you that is suitable for you. We would like to do the research in a way that best works for you and your [son/daughter].

Alternatively, please fill-out the reply slip, which is attached to this letter, and post it in the stamped-addressed envelope. Thank you very much for taking the time to read this information sheet.

Please return this slip using the enclosed envelope.

I/We would like to participate in the research. My name is

I would like the researcher to contact me on:

The best times to contact me are: _____.

Any additional information I would like the researcher to know about:

Consent form Nearest Relative/Guardian or Welfare Attorney study two

Transitions in adulthood for people with severe or profound intellectual disabilities

Consent form (nearest relative or guardian or welfare attorney), version no. [2], date [09/02/2018]

Nearest Relative/Guardian or Welfare Attorney CONSENT FORM

Transitions in adulthood for people with severe or profound intellectual disabilities

The form has several parts. You are under no obligation to give consent to all parts if you wish for your son/daughter to participate. You are free to choose whichever of the following options you wish to consent to but the researcher will only be able to include participants who consent to sections 1, 2, 3, 8 and 9.

Participant ID:

[Insert contact details of person taking consent]

Please initial box

1. I confirm that I have read and understand the information sheet (PIS (The family unit as participants) version no 3 01/03/2018) and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my relative's participation is voluntary and that I am free to withdraw my relative at any time, without giving any reason and without my relative's medical care or legal rights being affected. ☐
3. I understand that the researcher would like to access documents that hold information about my relative's transition to adult services and that she would like to talk to others about the transition. I give permission for the researcher and her supervisors to have access to those documents and to talk to others about the transition. ☐
4. I agree for the researcher to do observations of my relative. I understand that I am free to withdraw my consent at any time, without giving reason and that the best interest of my relative has priority in the decision. ☐
5. I agree to my relative taking part in the above study. ☐
6. I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor (the University of Edinburgh) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records ☐

Transitions in adulthood for people with severe or profound intellectual disabilities
Consent form (nearest relative or guardian or welfare attorney), version no. [2], date [09/02/2018]

I confirm that I am the nearest relative for –

and that no other nearest relative or welfare attorney or guardian exists.

Relationship to person: _____.

_____ Name of Person giving consent	_____ Date	_____ Signature

_____ Name of Person taking consent	_____ Date	_____ Signature

1x original – into Site File; 1x copy – to Participant

Consent form parents/guardians study two (consent to their own involvement in the study)

Transitions in adulthood for people with severe or profound intellectual disabilities
Consent form (parents/guardians), version no. [2], date [09/02/2018]

CONSENT FORM

The form has several parts. You are under no obligation to give consent to all parts if you wish to participate. You are free to choose whichever of the following options you wish to consent to but the researcher will only be able to include participants who consent to the first four sections and the last two. This form relates to your own involvement in the research. You will be asked to fill in another consent form on behalf of your [son/daughter].

Participant ID:

Please **initial**

box

I confirm that I have read and understood the information sheet (PIS (The family unit as participants), version no 3, 01/03/2018, as specified in the document header) for the above study and have had the opportunity to consider the information and ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

I agree to be interviewed and for the interviews to be recorded. I understand that the recordings will be stored safely at the University of Edinburgh and deleted at the end of the research project. I agree to anonymised quotes being used within any publication of findings.

☐

I agree to give access to documents that hold information about the transition process.

☐

I agree for the researcher to join group discussions and meetings and for her to record those. I understand that the recordings will be stored safely at the University of Edinburgh and deleted at the end of the research project. I agree to anonymised quotes being used within any publication of findings.

☐

I agree for a second student to help the researcher analyse the anonymised transcripts and documents.

☐

I agree to take part in the above study

☐

I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor (the University of Edinburgh) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records

☐

Name of Participant

Date

Signature

Transitions in adulthood for people with severe or profound intellectual disabilities
Consent form (parents/guardians), version no. [2], date [09/02/2018]

_____	_____	_____
Name of Person taking consent	Date	Signature

Original to be retained in site file. Copy to be retained by the participant.

I would like to be informed about the research findings and publications in the following way:

Transitions into older age
Participant Information Sheet, version no [1], 02/04/2018



[Paula Jacobs,
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Medical School (Doorway 6)
Teviot Place
EH8 9AG Edinburgh,
07957 281207
s1368461@sms.ed.ac.uk]

Participant Information Sheet

Transitions into older age for adults with intellectual disability and severe communication difficulties: Professionals' views

You are being invited to take part in a research study. Before you decide whether or not to take part, please take time to read the following information carefully.

What is the purpose of the study?

The research aims to explore the views and experiences of professionals who support adults with intellectual disability and severe communication difficulties on their journey into older age. It aims to explore how old age looks like for adults with intellectual disability and the role professionals play in supporting the transition into older age. The research is particularly interested in practice relating to people with very limited communication abilities, and where incapacity to make informed decisions might be an issue.

Why have I been asked to take part?

You have been asked to take part as you are a professional who has experience in supporting adults with intellectual disability on their journey into older age.

What will I have to do?

The researcher would like to interview you and other professionals in your organisation, who are willing to take part. The researcher hopes to do one individual interview with you about your views and experiences (around 60 min). Interviews will be recorded on a digital recorder, so the researcher can transcribe them and you are free to decide what you would like to share.

Additionally, the researcher would like to conduct one group discussion to reflect together and share different perspectives. You can choose to participate in either the individual interview or the group discussion or both.

Do I have to take part?

No, it is up to you to decide whether or not to take part. You are free to withdraw your consent at any time and without giving a reason. However, if you withdraw your consent once the research has been completed we would use the anonymised content of information but would exclude you from any further part of the research.

What are the possible benefits and disadvantages of taking part?

We hope that you feel this is a valuable area of research. The project provides the opportunity to share your experiences.

If you feel that you need more support and practical information about issues that have come up during the research then the researcher has identified a number of organisations that are available to offer support, details of which are given at the end of information sheet. If you have any concerns about standards of care or the

wellbeing of the people you care for then the researcher will follow vulnerable adult protection procedures and inform her supervisors and the local authority.

Will my taking part in the study be kept confidential?

Yes, all the information we collect during the course of the research will be kept confidential and stored securely. The only exception would be if you tell the researcher that a vulnerable adult is at risk, or that you have concerns about standard of care. If that happened, the researcher would follow standard adult protection procedures and/or relevant local authority policies.

Interviews and Group discussions will be recorded using an encrypted and password protected audio recorder. No identifiable data will be published or will be accessible to others except the researcher and her supervisors. All identifiable information (such as names of service users, information relating to participants, locality or details about the organisations) will be removed from interview and discussion transcripts. The transcripts of the interviews and discussion group **once all personally identifiable information is removed**, will be stored at Edinburgh University long-term secure storage. This will be held for 5 years.

What will happen to the results of the study?

The study will be written up as a thesis, for a PhD and findings in the research could be communicated to a wider audience.

If you would like then a summary of the interviews and group discussion and a final summary of the research project will be sent to you.

Who is organising the research?

This study is being organised by Edinburgh University. The researchers name is Paula Jacobs and her supervisor is Dr Ken MacMahon (Senior Lecturer/ Clinical Psychologist). He can be contacted on: 0131 651 3960 or ken.macmahon@ed.ac.uk

If you would like to discuss the study with someone independent of the study please contact Dr. Angus MacBeth on: 0131 651 3960 or angus.macbeth@ed.ac.uk and if you wish to make a complaint about the study please contact the University of Edinburgh's Research Governance team via email at: resgov@accord.scot

The School of Health in Social Science ethics committee have reviewed the study proposal.

How do I take part?

Please contact the researcher, Paula Jacobs, on: 07957 281207 or email: s1368461@sms.ed.ac.uk. She will arrange a time and place to meet with you that is suitable for you. We would like to do the research in a way that best works for you.

Thank you very much for taking the time to read this information sheet.

Available supports:

- Contact a family
- Support for professionals working within disability services: 0131 659 2930
- Cruse Bereavement Care
- Bereavement helpline: 0808 8081 677
- Alzheimer Scotland
- Dementia helpline: 0808 808 3000
- The challenging behaviour foundation
- Organisation that offers support and guidance to those who support people who present behaviour that challenges: 01634 838739

Appendix 3: Data Management Plan examples

Data Management Plan study one

1. Data Capture

What data will be generated or reused in this research?

A variety of data will be collected around 2-3 cases. As the data collection will need to follow the decision-making process the researcher will need to be flexible about methods used and how and when to collect data. The exact method and amount of data collected will depend on the participants involved and the researcher will need to try out what works for them, thus being flexible and responsive to individuals. The researcher will use Yin's (2002) data collection methods as guidance. Table 1 will give an overview of methods and data that might be collected, yet this depends on participant's preferences, the process and on consent.

Method	Data
Interviews	Audio recordings
Observations	Vignette format Sheets of paper Word document
Documents (Meeting notes, letters, diary entries, reports, plans)	Anonymized copies of documents Anonymized copies as word or pdf files
Archival records	Anonymized copies of documents Anonymized copies as word or pdf files
Group discussions	Audio recordings Notes (sheets of paper and word files)

Interviews

Interviews will be conducted with approx.. 8 participants per case and will last approximately an hour each. Follow-up interviews might take place depending on the development of the research process. The researcher will use audio recordings to record interviews. Audio files will be recorded in mp3 format. 1 hour of audio recordings will approximately consist of 600MB.

Observations

The researcher will conduct between 2 to 6 observations per case, lasting about 30 min to an hour. She will write down her observations on sheets of paper using a vignette format.

Documents and Archival records

Relevant documents and archival records will be obtained from those involved. Those will be anonymized and kept as paper copies and word or pdf files.

Group discussions

Group discussions will be recorded as audio files in mp3 format and additional meeting notes will be written on sheets of paper and typed up as word documents.

2. Data Management

How will the data be documented to ensure it can be understood?

Interviews and Group discussions will be recorded using two audio recorders. The researcher will use sheets of paper to write down her observations. Those will be safely carried to and from interviews/observations. Documents and reports will be obtained from the settings where they are stored and if possible copied and anonymized at the original storage facility. Hard copies will be carried back to the university and digital copies will be carried back on a USB stick and stored on the university's data storage. Once this has been completed they will be deleted from the USB stick.

As part of the data analysis phase the researcher will use a software called Nvivo to work on the transcripts. Nvivo is supported by university computers and anonymized transcripts will only be accessed via the university system.

The researcher will only use Nvivo to work on the anonymised transcripts and not upload any other files or data.

A system for organising and storing the data will be used to ensure consistency.

Each research participant will have an identification number. All digital and physical data will be labelled with the case's and participants' unique identification number, type of data (e.g. interview) and the date. All data files will be arranged in electronic folders according to the case itself and according to individual participants within one case (e.g. Case 1, participant 1 = C1P1; Case 2, participant 6 = C2,P6).

Where will the data be stored and backed-up?

The data will be stored at the School of Health and Social Science server that is supported by IS services. This ensures that the data are held securely and are regularly backed-up. The data in the Research Data Management (RDM) file-store is automatically replicated to an off-site disaster facility and also backed up with a 60-day retention period, with 10 days of file history visible online.

Physical copies of documents, records, notes, observations will be stored inside a locker at the researcher's department. The researcher will have one key and the researcher's supervisor will keep a second one.

3. Integrity

How will you quality assure your data?

There is no single, accepted way of carrying out qualitative research depending of the nature and design of each study. The data will be analysed in relation to the research questions. Therefore, the data will be examined through a rich and detailed analysis.

Triangulation

The triangulation of multiple data sources to corroborate findings is a central element of case study research (Yin, 2013). Triangulation will involve the use and comparison of multiple qualitative data collection methods (as can be seen in table 1) in an attempt to determine similarity of the various results found. Triangulation allows for stronger conclusions to be drawn from the study findings in the absence of a control group (Bergen & While, 2000).

Semi-structured interviews

The researcher will use semi-structured interviews. Semi-structured interviews will be used, as they are open enough to give participants space to highlight topics and issues of their own concern, while a structure of guiding questions will allow for the research to be grounded in

the standing literature and to make comparisons to existing findings. The same Interview schedule will be used with all participants.

Reflexive bracketing

Additionally, this project will use reflexive bracketing, a methodological approach used in phenomenological research (Ahern, 1999). It involves laying out the values, biases, assumptions and political preferences that guide the researcher's perception of the world. Honest reporting of potential biases functions as a mechanism by which the researcher and reader can become aware of existing predispositions and allowing the implementation of measures to identify and compensate for these.

Validity of findings

After the transcription phase and anonymization of data, the researchers two supervisors will be involved and another student of the department will be introduced to the analysis. This is to assure reliability and validity of findings. As the researcher works with the text in an interpretative way by focusing on the most important and interesting data whilst reducing the volume, a second researcher is valuable at this stage to help ensure that the most relevant data are kept and to increase sensitivity and openness towards the meanings within the data. (Cassidy, 2010; Smith and Osborn, 2007)

4. Ethics

How will you manage any ethical and IPR issues?

As this research involves a sensitive topic, where specific issues, such as conflict of opinions, lack of resources, challenging behaviour, concerns over quality of care, placement breakdowns or struggles with care demand; may arise there will be full consideration of the potential ethical issues surrounding the study. All studies will be planned and implemented in accordance with University of Edinburgh and British Psychological Society guidance. Due to the complexity of involving people with profound ID and families and carers and the novelty of doing so, Nind's (2008) guide on conducting qualitative research with people with profound ID will be followed.

Individuals and organizations will be anonymised in the process of transcription. Names of other people, places, life events and organisations will also be anonymised to make an identification of participants impossible. Pseudonyms will be used during transcription and while noting down observations

5. Retention and Preservation

Which data do you plan to keep and for how long? How will the data be preserved?

Data will be retained, securely, within the University of Edinburgh data store for a period of five years following completion of the project. Records will be safely deleted or securely shredded past those five years following data protection procedure of the University of Edinburgh. Data stored on the external hard drive and laptop will be deleted once the research is completed and data has been moved to the university's data store.

The researcher will do any transcribing and handling of the data by accessing the university's data store. The data will be stored in 3 different and secure ways to avoid data loss: On the school's online storage system, a laptop and an external hard drive. A university laptop will be used to store audio files, word and pdf files, photographs and videos. The researcher will use the university's laptop to work on transcribing the data. University laptops are fully encrypted by IS services for researchers using sensitive data. Data will not be stored on non-university

laptops or other devices. The university laptop will be kept in the researchers locker at her department when she is not working on it. Once data is stored securely on the university's network it will not be taken or accessed outwith university premises or outside its network. (E.g. not be accessed through public services such as gmail or outlook). Any lost or stolen devices belonging to the researcher (such as mobile phones) which are synchronized to office365 will be reported stolen to IS services immediately, who will assist in deleting any possibility for sensitive data to be accessed by third parties. The researcher will use two audio recorders to record the interviews and sheets of paper to write down her observations. Those will be safely carried to and from interviews/observations in a suitcase with a lock. The researcher will store those in the locked cabinet at the department and after an interview or any observations she will immediately travel back to the university to store those safely and securely. At the university the data from the audio recorders will be uploaded on to the laptop, the external hard drive and stored on the university's storage facility. Once this has been done the files will be deleted from the audio recorder.

6. Sharing and Publication

Which data will be shared and how?

Once the analysis is complete, the findings form part of the researcher's PhD thesis and will be submitted to the University of Edinburgh. Findings might also be presented at conferences or might form part of journal articles to be published during the researchers 3 year PhD or after.

The thesis might later be edited and prepared for publishing purposes. Participants will be made aware that there is a possibility of findings to be published or presented outside of the researcher's thesis. If wished, participants will be kept up to date with the progress of the finished work.

Data Management Plan study three

1. Data Capture

What data will be generated or reused in this research?

The researcher will use audio recordings to record interviews and group discussions. Approximately 5 to 12 interviews and two group discussions will be conducted which will last approximately 1 hour each.

2. Data Management

How will the data be documented to ensure it can be understood?

Interviews will be recorded using an encrypted and password protected digital recorder. Interviews will be transcribed and anonymised. As part of the data analysis phase the researcher will use a software called Nvivo to work on the transcripts. Nvivo is supported by university computers and anonymized transcripts will only be accessed via the university system.

The researcher will only use Nvivo to work on the anonymised transcripts and not upload any other files or data.

A system for organising and storing the data will be used to ensure consistency while ensuring confidentiality. Each research participant will have an identification number. All digital and physical data will be labelled with the organisation's and participants' unique identification number, type of data (e.g. interview) and the date. All data files will be arranged in electronic folders according to individual participants within each organisation (e.g. Organisation A, participant 1 = OAP1; Organisation B, participant 6 = OB,P6). The original list linking participants with identification number will be stored in a separate encrypted folder on the university's DataStore and a hard copy will be stored together with consent forms in the office of the researchers supervisor at the School of Health in Social Science (locked).

Where will the data be stored and backed-up?

The data will be stored at the School of Health in Social Science server that is supported by IS services. This ensures that the data are held securely and are regularly backed-up. The data in the Research Data Management (RDM) file-store is automatically replicated to an off-site disaster facility and also backed up with a 60-day retention period, with 10 days of file history visible online.

The data will be stored in 3 different and secure ways to avoid data loss: On the school's online storage system DataStore (within encrypted and password protected folder), an encrypted and password protected laptop and a password protected and encrypted external hard drive (stored in locked filing cabinet of supervisors office). After conducting interviews at each organisation the researcher will travel back to the university (carrying audio recorder and consent forms in a locked suitcase) to store audio recordings safely and securely. The recordings will be transferred to the encrypted laptop, the University's secure network DataStore and an encrypted external hard drive.

Consent forms will be kept in the locked filing cabinet in the office of the researchers supervisor. Addresses, postcodes, emails and phone numbers will be used to communicate with participants and to provide feedback on findings as wished by participants. Details of those will be safely and securely stored together with consent forms and stored in locked suitcase while being transferred from the research site to the university.

The researcher will use the university's laptop to work on transcribing the data. University laptops are fully encrypted by IS services for researchers using sensitive data.

Data will not be stored on non-university laptops or other devices. Once data is stored securely on the university's network it will not be taken or accessed outwith university premises or outside its network (e.g. not be accessed through public services such as gmail or outlook). Any lost or stolen devices belonging to the researcher (such as mobile phones) which are synchronized to the researchers student email will be reported stolen to IS services immediately, who will assist in deleting any possibility of email correspondence to be accessed

3. Integrity

How will you quality assure your data?

The researcher will use semi-structured interviews to gain access to the experiences of professionals that support adults with intellectual disabilities in the transition to old age. Semi-structured interviews will be used, as they are open enough to give participants space to highlight topics and issues of their own concern, while a structure of guiding questions will allow for the research to be grounded in the standing literature and to make comparisons to existing findings. The same Interview schedule will be used with all participants.

After the transcription phase the researchers two supervisors will be involved and another student of the department will be introduced to the analysis. This is to assure reliability and validity of findings. As the researcher works with the text in an interpretative way by focusing on the most important and interesting data whilst reducing the volume, a second researcher is valuable at this stage to help ensure that the most relevant data are kept and to increase sensitivity and openness towards the meanings within the data (Cassidy, 2010; Smith and Osborn, 2007).

There is no single, accepted way of carrying out qualitative research depending of the nature and design of each study. The interviews will be recorded and data analyzed in relation to the participants' experiences. Therefore, the data will be examined through a rich and detailed analysis.

4. Ethics

How will you manage any ethical issues?

For her analysis and within her write up the researcher will only use anonymised transcripts of the audio recordings.

Data that still holds identifiable information will not be included in the presentation of the research.

5. Retention and Preservation

Which data do you plan to keep and for how long? How will the data be preserved?

Only anonymized data will be retained. Audio-recordings and original data will be securely destroyed once the study is completed. Anonymized data will be retained, securely, within the University of Edinburgh data store (DataVault) for a period of five years following completion of the project. Records will be safely deleted or securely shredded past those five years following data protection procedure of the University of Edinburgh. Data stored on the external hard drive and laptop will be deleted/destroyed once the research is completed and data has been moved to the university's DataVault. Dr. Kenneth MacMahon will be responsible for the data if the researcher leaves the university within the 5 year period.

Access to data post completion by other researchers will not be given.

6. Sharing and Publication

Which data will be shared and how?

Once the analysis is complete, the findings form part of the researcher's PhD thesis and will be submitted to the University of Edinburgh. Findings might also be presented at conferences or might form part of journal articles to be published during the researchers 3 year PhD or after.

The thesis might later be edited and prepared for publishing purposes. Participants will be made aware that there is a possibility of findings to be published or presented outside of the researcher's thesis. If wished, participants will be kept up to date with the progress of the finished work.

Consent relating to storage, access and the publication of different data sources will be included within the consent forms (see consent forms).

Appendix 4: Risk assessment example study two



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Risk Assessment

This risk assessment is drawn up to assure that the intended research is safe for participants and the researcher. Its aim is to clarify responsibilities, plan for safety in the research design by taking into consideration precautions, strategies for handling risk situations, how to conduct data collection and how to establish debriefing and support after any events. The risk assessment will not be shared with anyone apart from the researcher and her supervisor. Individual Home Visit Risk Assessments will be written up by the researcher and her supervisor. Individual versions will be securely stored with the researcher's supervisor in a locked filing cabinet in a locked office at the University of Edinburgh.

Responsibilities:

The researcher is responsible for making sure that participants are aware of the purpose and aims of the study. Furthermore she is responsible for explaining the research design and how data will be gathered and stored, how confidentiality will be achieved, who will have access to data and what will happen to the finished study, as well as making participants aware of possible disadvantages of taking part in the study and what kind of support can be accessed.

It is the participant's responsibility to read the provided Information Sheets and to decide if they feel able to voluntarily take part in the interviews.

The Study:

The study will use an information leaflet to introduce the subject matter followed by a variety of data collection methods.

Interviews

Semi-structured interviews were chosen to gather data on a planned range of topics, while still giving freedom to the participants to provide information that is most meaningful to participants.

Group discussions

Group discussions may involve a number of different stakeholders. They might be facilitated within the family setting, involve adult services and families or other professionals. Again this depends on the individual cases and what appears to be most suitable.

Documents

Specific documents are documents that hold relevant information about the person and the transition process. Those might be Personal Plans, Assessments, Meeting notes, letters. Those might consist of current documents or past documents. The documents are third party documents and there may be restrictions placed on the researcher about how and where she can use these. To use specific documents during the analysis and to report findings permission needs to be obtained by the original authors and/or organizations. If permission is declined, the documents will not be used for analysis. However, the researcher may speak to participants about their views on specific documents.

Observations

The researcher might conduct observations of the person with severe or profound ID in settings that appear most suitable for all those involved. Due to the sensitive nature of conducting observations with adults that lack capacity to give consent, observations will need to be carefully planned in partnership with those closest to the person. Observations will not be conducted if it is felt that they are unsuitable and pose risks of being intrusive and unsettling to the person and others involved.

Physical artefacts

Physical artefacts will be collected and may consist of a range of expressive artefacts such as photographs, pictures, videos, or other art and crafts material. The researcher will not use any original pieces for her analysis but photographs or copies will be taken of relevant items. Pieces that are identifiable will not be used in presenting the findings but anonymised artefacts (such as artwork) might be included if consent is given.

Strategies for handling possible risks for participants

The initial letter will have prepared participants for the study and follow-up conversations can be requested. Support groups and contact numbers will be identified and offered in cases where the study evoke great distress. The activity (e.g. interview, group discussions, observation, collecting art pieces or documents) will be stopped if participants get distressed.

In the end of any meeting the researcher will ask participants how they found the experience and how they are feeling. If participants show signs of distress the researcher will guide participants to contact the relevant support services.

Strategies for handling possible risks for the researcher

In the beginning of any meeting it is made clear that the researcher is not a trained counselor and that she is unable to support the participants with feelings of distress and needs to talk through their experiences on a counseling basis. It will be made clear that the identified sources will be better able to assist with such wishes

Home visits

Organisations which assisted in recruitment know the families well and will assist the researcher in planning any home visits in cases where this seems to be the only option for participants to imagine being able to meet with the researcher. For every home visit a risk assessment will be written beforehand and talked through with the researcher's supervisor. The researcher has conducted home visits for two previous studies and she and her supervisor have experience with home visits and protocols and procedures associated with any risks.

A call-in time before and after the visit will be arranged, contact details of the participants will be shared with the researcher's supervisor. The recruitment organizations' knowledge of any issues in relation to home visits will be used to assess any risks and find a solution to conduct the research in the safest way possible for the researcher and participants. In cases where risks associated with a home visit seems too high and an alternative setting can not be found, the researcher will refrain from home visits. (see checklist at the end of document)

Conducting the Interviews

All content of the research will be confidential but participants will be made aware that any information which raise issues of adult protection or risks to others, will need to be reported and shared with relevant services in accordance with the BPS Code of ethics and conduct.

Breaches of confidentiality will be necessary in cases which compromise:

- (a) the safety of participants;
- (b) the safety of other persons who may be endangered by the participants behaviour;
- (c) the health, welfare or safety of children or vulnerable adults.

In cases where any information shared raises issues of safety of vulnerable adults, participants will be made aware of this. The researcher will explain that this information will need to be shared with the researcher's supervisor and Local Authorities Adult Protection Officer. In those cases confidentiality will be breached.

Policies on Whistleblowing and Discipline and Procedure will be followed if any information shared raises concerns about the standard of care.

Support and Contact after the Interviews

After any research meetings the researcher will stay and continue to talk to the participants about other topics to slowly lead the conversation away from the research topic and not leave participants overwhelmed with emotions, which might have been evoked by the meetings.

The researcher will make sure participants have her contact details so that they can contact her with any concerns and questions, which might come up after interviews or other meetings.

The following support services have been identified for participants who feel they need support with their experiences on a level out with the research.

- PAMIS Family support service:
Fife - Maureen McClelland t: 01592 551 310
Greater Glasgow & Clyde - Elizabeth Platt t: 0141 572 0782
Grampian - Amy Anderson t: 01569 764 221
South Lanarkshire - Michelle Morrison & Lesley McLaren t : 01698 420 411
Tayside - Maureen Phillip t: 01382 385 154

- The Challenging Behaviour Foundation:
 Family Support Service for practical information or emotional support:
 0300 666 0126 or email us at: support@theCBF.org.uk
 Monday – Thursday: 9am – 5pm and Friday: 9am – 3pm

- Counselling Directory:
 A confidential service that encourages those in distress to seek help:
www.counselling-directory.org.uk

- Contact a family
 Support for professionals: 0131 659 2930
 Local support groups for families in Scotland: 0131 659 2930

The researcher has extensive experience in working with professionals, families and people with profound ID. Furthermore, she is working for a phone counselling line and has received training and has experience in dealing with distressing topics and managing child protection issues.

HOME VISIT RISK ASSESSMENT/ MANAGEMENT PLAN

The risk assessment will not be shared with anyone apart from the researcher and her supervisor. Risk assessments will be completed by the researcher and her supervisor. Information relating to possible risks of home visits will be discussed with recruitment organisations using the home risk assessment format. The researcher will ask senior staff or service managers the questions listed within the home risk assessment. The researcher will refrain from asking for details but will only attempt to clarify if the organisation has any concerns in relation to home visits. No specific service records will be accessed or viewed by the research team. Risks relating to home visits will not be discussed with participants. Copies of risk assessments will be retained within a locked filing cabinet in a locked office at the University of Edinburgh. Risk assessment must be carried out prior to any initial home visit taking place. The researcher must ensure the following steps are taken and the checklist complete.

Risk factors	Yes	No	Highlight Concerns/ Give Details
Does the organisation know the participants well and has advised low risk visit?			

Have you advised your supervisor of your whereabouts and your expected time of return?			
Does the family have a known history of assault?			
Is the family likely to be under the influence of substances?			
Is the family known to own or carry weapons?			
Does the participant live alone?			
Are there likely to be other individuals in the home, at the time of the visit, who could present a risk?			
Are there any adult protection issues?			
Environmental Factors	Yes	No	Highlight Concerns/ Give Details
Are you familiar with the location/neighbourhood?	x		
Is the location and entrance clearly visible?	x		
Is the location and entrance well lit?	x		
Will it be daylight at the beginning and the end of the visit?	x		
Is the building outside police recognised high crime/drug use areas		x	
Are there any risks posed by animals in the home?		x	
Are there any smoking or fire risks?		x	

PARTICIPANTS DETAILS

Participant name:	
Address:	
Locality:	
Date of visit:	

RISK ASSESSMENT OUTCOME/ MANAGEMENT PLAN

Have any areas of risk been highlighted? (please circle and summarise)
Any checked shaded areas on the checklist.

YES NO

Completed By (Signature):

Date:

Supervisor (Signature):

(Signature):

Review Date:

If yes, is further risk assessment required? (please circle)

YES NO

If yes, provide details of the risk management plan:

Appendix 5: Interview guide examples

Semi-structured interview guide study one

The interview schedule is developed to guide participants toward some key themes, while giving space for individual experiences and variations. The interview will consist of the following questions and possible prompts. Questions that only refer to professionals have a (prof) behind them and questions only relating to family members a (fam).

Questions have been revised with two parents of a young woman that went through the transition a few years ago.

1. Can you tell me a bit about the young person?

- How would you describe him/her?
- How does the person's life/day look like?
- Who is the person close to? What kinds of relationships does the person have?
- What does the person enjoy? What does he/she struggle with?

2. Can you tell me about your relationship to the young person?

- What do you do together?
- How does your life as a family look like? (fam)
- How long have you known the young person? (prof)
- How well would you say you know the person? (prof)
- How would you describe your role in the young person's life?

3. Can you tell me about the approaching transition to adult services?

- How do you feel about it?
- What will happen over the next months? How does the transition process look like?
- Who will be involved? What are their roles?
- In an ideal scenario what would you like to see happening? What stands in the way of this ideal?
- Why do you think this would be the best scenario for the young person's future?
- What do you think is needed for a successful transition?
- What do you need/want? What does the young person need/want? (fam)
- What do you need/want? What does the young person need/want? What does the family need/want? (prof)
- What will be your role in the transition process?
- How do you feel about acting on behalf of the young person?

- How do you think other people involved make their decision? What information do they use?
 - How do you think the transition will affect the young person?
4. Can you tell me about any meetings you had so far?
- Who was there?
 - What did you think about the meeting?
 - Was it helpful? Why?
5. How will all those involved work together during the process?
- How are decisions made? How are plans made?
 - Who is involved and what are the different roles and responsibilities?
 - What is needed to work together well?
 - What might stand in the way of working together?
 - How is the young person involved in the decision-making?
 - How is conflict dealt with?
 - Whose voice do you think is heard most?
6. How do you think the young person's future will look like?
- What do you believe adult life is like for people with profound ID?
 - What do you think will happen now and then?
 - What are your hopes, wishes and concerns Now? And for the future?
 - How is this affecting you?
 - What will be your role in the young person's adult life?
7. Is there anything else you would like to tell me?

Semi-structured interview guide for LA Managers study one

1. Can you tell me a bit about your role?
- What are your responsibilities?
 - What is your role in the transition process?
 - How do decisions you make impact on those involved (families, young person, other professionals)?
 - How do you think other people involved make their decision? What information do they use?
 - What informs the decisions you make? (policies, senior management, briefing documents, strategic documents, guidelines) Can you name a few specific ones?
 - What options are available for young people from X? How do families or professionals know about the services that are available? How do you work together with adult service providers?
 - What makes a service a good service?
 - How are budgets decided on?
 - How do you know about the number of young people and their needs to be able to plan ahead for services needed?

2. What do you understand under the term severe or profound Learning Disabilities?
 - What cases come to your mind?
 - How do individual's needs look like?
 - How do individual's lives look like?
 - What kind of relationships do individuals have?
 - How do the needs of individuals with severe or profound ID differ from other groups or do they?
3. Can you tell me about the transition process from children to adult services?
 - How should a transition process look like? (use Transition Forum timescale)
 - Does it always happen in the ideal scenario? What stands in the way of this ideal?
 - Who is involved? What are their roles?
 - What do you think is needed for a successful transition?
 - How is the young person involved?
 - How is the family involved?
 - Can you tell me about the assessment process of social workers and how these inform budget or placement decisions?
 - It seems to me that families either continue to look after their adult children at home and live together or that young people move out and are then accommodated outwith the family? Can you tell me a bit about those two different models? What happens if families at first want their children to continue to live with them but then feel that the day service or respite provision of 35 nights is not enough?
4. How will all those involved work together during the process?
 - How are decisions made? How are plans made?
 - Who is involved and what are the different roles and responsibilities?
 - What is needed to work together well?
 - What might stand in the way of working together?
 - How is the young person involved in the decision-making?
 - How is conflict dealt with?
 - Whose voice do you think is heard most?
5. How do you think adult life is like for young people with severe or profound ID?
 - Parents seem to be strong advocates for the young people. What happens in cases where parents are unable to fulfil that role. Who will advocate on behalf of the young person?
6. Is there anything else you would like to tell me?

Semi-structured interview guide study three

1. How would you describe the transition into older age for people with intellectual disability and severe communication disabilities you support?

- What do people's lives look like?
- What is your role in supporting the people you care for?
- How do you support the people you care for?
- How do you notice that people are getting older and how do needs change?

2. Do you support people with severe communication difficulties entering older age, where there are issues around their capacity to make decisions?

- How do you assess capacity?
- How do you support those who are unable to make their own decisions?
- Can you give an example of the kind of decisions that might need to be made?
- How do you feel about acting on behalf of the person you support?
- How would you define 'best interest'?
- What information do you use to make or support decisions?

3. What do you feel are the strengths of your organisation in supporting those with severe communication difficulties transitioning into older age?

- What is good practice?
- What stands in the way of good practice?
- What do you feel is needed to provide good support? (Now and at later stages in old age) What stands in the way to offering the best possible support?
- What are your concerns and hopes for the people you support?

4. Who is involved in people's lives and how do different professionals and family members work together?

- What kinds of relationships do people have you support who are older?
- Which professionals are involved in people's lives?
- How do different individuals work together in supporting the people you care for?
- What are different roles and responsibilities?
- Whose voices are heard most?

- How is conflict dealt with?

5. How are people with intellectual disability and severe communication difficulties involved in decision-making?

- What kind of different decisions might need to be made?
- How are people involved in everyday decision-making?
- How are people involved in 'bigger' decisions? (such as medical treatment, accommodation)
- How do people you support express themselves and communicate their likes and needs?

Appendix 6: Recruitment flowcharts

Flowchart recruitment study one and two

A letter was sent to headmasters or senior professionals of identified recruitment organisations outlining the research and requesting them to identify possible participants. After considering the research through their own internal procedures organisations informed me if they were willing to participate.



I met with headmasters or senior professionals of the organisations to clarify the inclusion criteria for families and to discuss the research protocol and answer any questions.



I forwarded an Information Pack to the organisations to be passed on to possible participants. (The Information Pack was initially addressed to parents and their children with severe and profound ID. Other relevant professionals or other family members and/or important people were identified later, once families and guardians had given permission. See appendix)



Participants were selected from feedback and those interested were contacted via phone to answer questions. In the initial conversations I highlighted the wish for a holistic data collection.

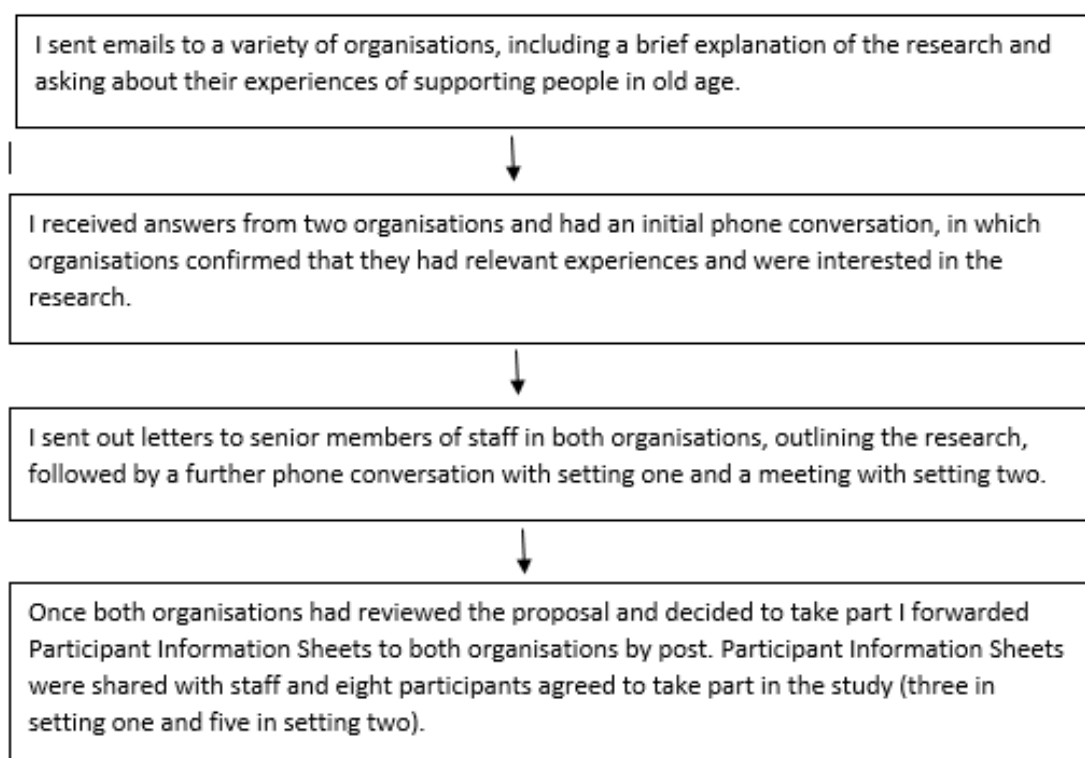


If families continued to show an interest to take part in the study during the phone conversation we then arranged a first meeting.



During the initial meeting the Information letters and Consent forms were discussed with parents and other people relevant to the decision-making were identified (such as teachers, social workers, support workers). Information sheets were sent out to identified professionals and others after the meeting. Formal permission of agencies such as social work was obtained by following their own procedures.

Flowchart recruitment study three



Appendix 7: Contact Summary Form examples

Contact Summary Form (Miles and Huberman, 1994), study one

Contact type: Interview Clinical Psychologist at Hospital young person's unit

Visit: 1st visit to meet clinical psychologist

Site: Hospital

Contact date: 12.09.2017

Today's date: 13.09.2017

Written by: Paula Jacobs

1. What were the main issues or themes that struck you in this contact?
 - X's low mood and self-injurious behavior is a dominant theme in his life and dominates descriptions of who he is
 - Joint up work of professionals. Doing as much as they can within frame and possibilities given by funding and budgets
 - Concern of decrease within respite about to happen. Respite as a big factor in decision to do the transition now instead of going along with school. (need to reflect that within timeline. I think this is on the level of choosing X over X to maximize hours possible, to have less changes for X in moving all into one service and in having more hours now than they would have with X being at school and reduces respite at X. X only respite option)
 - Consistency of high needs and levels of challenging behavior over the years and not seeing this being likely to change
 - Diagnosis of low mood based on analysis of behavior pattern
 - Well-coordinated collaboration between health and social care in this case on a practical level
2. Summarize the information you got (or failed to get) on each of the target questions you had for this contact.

Got some information on all target questions (see above). Participant's role more about supporting the family and professionals within their strategies and approaches to support X. Able to raise concerns about respite reduction but not in a position to challenge this further and sees the difficulties of professionals within social care needing to work within existing budgets. However, there has been some additional hours offered for X (but still a lot less than before)

Transition in terms of health care seems more flexible and able to respond to X's needs (e.g. waiting with transition of Clinical psychology and psychiatry just now). Speech and Language different case due to connection to school placement.

3. Anything else that struck you as salient, interesting or important in this contact?

Interesting theme of X would only want to be at home on couch but this is not in his best interest.

Can see X in a flat one day but importance of close family connection is highlighted

SW and parent emerge as main decision-makers

Transition so far has appeared to be positive for X (is doing quite well at X) but also thinks X has not realized that it happened just yet

4. What new (or remaining) target questions do you have in considering the next contact with this site?

Is this enough from a health perspective? Should I contact psychiatry?

Can only raise concerns: Maybe X has also some power to bring about change by showing if an existing package is working by escalating behaviour

Contact Summary Form (Miles and Huberman, 1994), study one

Contact type: Interview at participants home C3P1

Visit: 1st

Site: family home

Contact date: 10.07.2017

Today's date: 12.07.2017

Written by: Paula Jacobs

1. What were the main issues or themes that struck you in this contact?

Very respectful narrative of sons. In depth storytelling of the family's experiences starting from diagnosis till now.

Residential placements both experienced as very positive (school and adult services)

Very positive transition experience. Mother described that she thinks they have been so lucky due to being organized, well-informed, starting early and working with the system and professionals involved.

Interesting point made about residential being cheaper than program from home with outreach and respite on top. Not sure that is true.

Interesting contrast of residential and being different local authority.

Young person similar to young person in Case 2. Due to no challenging behavior maybe more opportunities. Easier for parents to 'let go' and greater possibility for independence.

2. Summarize the information you got (or failed to get) on each of the target questions you had for this contact.

Young person: Information framed within narrative of whole life story. Very clear picture of young person and who he is. Describing personality, likes and dislikes. Maybe clearer differentiating between him and family and his needs and family needs compared to other cases. Some involvement of young person within reviews and meetings and use of photographs and social stories. Explore more with professionals involved. Strong connection to brother with ID and autism but differentiation of their needs and personalities within interview.

Relationship to young person: Strong relationship. Advocating on behalf of young person very respectfully. Guardianship is in place. Strong bond but also already very focused planning of young person continuing to live outwith the family and wish to identify services and placement that mother trusts and where she feels her sons are safe, nurtured and happy.

Transition: Very positive experience. There appeared to be no issues of having an out of area residential placement. Didn't seem to be any struggle not to take up supported living accommodation or even community placements closer to family home (X etc.)

Meetings: Started to talk about transition within reviews early on. Main decision making between social work and family. School supportive in terms of passing on information, supporting visits of places and working with son more on life skills within last years. One placement that had been identified and worked towards fell through about a year before transition and although this was emotionally challenging another placement identified relatively smoothly and mother know more positive as this is a young adult placement instead of already for the rest of life and she feels it is more beneficial for young adult son and more suitable.

Working together: Very positive working relationships between all professionals. Involvement of many social workers and staff changes (4 to 5) but family positive about it.

Young Person's Future: Proactive and ready to start next transition process soon (placement ending at 25). Would like similar therapeutic community placement for son within adult life and older age.

3. Anything else that struck you as salient, interesting or important in this contact?

Clarity and positivity of process. Seeing residential placement as very positive. No issues in relation to son being looked after and social work involvement. Family still advocates and rights and looked after not resulting in social work identifying placement based on money and budget (fears case 2). Need to explore this more.

Mother talked about residential not having a good reputation but that she feels chosen setting is very positive and has a lot to offer for families and young people. Case 2 mother had mentioned she would have loved X to go to similar placement but it seemed to be out of her reach. Why?

4. What new (or remaining) target questions do you have in considering the next contact with this site?

Need to speak to professionals involved.

Talk to Social Work and their view on supporting out of area and residential placement.

Appendix 8: Example interview summaries for participants

Summary for participant in study two

Interview summary (written from a first person account with direct quotes from the interviews in *italics*)

*Lisa has been chosen as a pseudonym and organisations and places are anonymised.

Lisa

Lisa is 28 years old. She has a condition which means that part of her brain is missing. She has very limited vision and her mobility is affected. She also has epilepsy. Her developmental age is close to that of a 20 month old. *She can say a few words but she has her own meaning for what they mean and they are not necessarily what you might expect them to mean. For example, when she says 'hello' she might be meaning hello but she might also just be meaning that she is having fun.*

Lisa enjoys a variety of activities. She enjoys food and she enjoys walks. *You can take her on short walks but if it was longer than you need to take a wheelchair.* She likes going on car journeys as she seems to like when the car is moving and there is bouncing about. *She used to do a lot of sailing and she used to enjoy it when the boat was moving.* But she can find it challenging when the car needs to stop and stands still for some time.

Lisa likes social environments. *She likes hanging out with family, social groups and if we have friends or family round to my parents' house then she enjoys talking with new people. She is famous in her [day centres] for hanging out in the social spaces. She will hang out in the café and interact with other people who are maybe not expecting her to interact with them. She will quite often just wander over to where the excitement or the noise is.* This has become a little bit of an issue if we take her to a restaurant or a café.

Life Now

Lisa goes to two different local day centres from Monday to Friday during the day. She lives at home with our mum and dad. *She also goes to groups with various care workers. She has quite a strong support base around her. She has a couple of good carers who are fairly regular plus she has now been going to her day care centres for a while and she has got quite used to them.*

She has two other disabled people who she spends a lot of time with. They often socialise and our families know each other.

When Lisa was younger she used to sleep in her own room but since a while she has found it more difficult to sleep. *She would cause a racket sort of bang her head quite destructively against the wall, make loud noise. So now my parents they like to sleep with her and they sort of take it in turns so she gets a settled sleep.*

Relationship to carers

Continuity is important for Lisa. For example, her carer at one of the day centres has looked after her for several years *and I think they both know what to expect from each other. Occasionally there have been times where she flatly refuses to do activities and they can't do too much about it. But with this carer she already got the rapport. She knows what the script is and I think it helps.*

Her carers can find her behaviour quite challenging at times but I guess they now know what to expect. Lisa knows what to expect and they formed quite a meaningful relationship which adds to Lisa's life.

My role

I am her older brother. *I see her fairly frequently at special family events plus every now and then I go home for a night or a dinner. She still definitely recognises me, knows who I am and often gets quite excited to see me.*

I am also registered as her substitute guardian *so if anything would happen to one or both of my parents I would be stepping into a guardianship role.* I am trying to support my parents within the current transition process. *It is proving to be a very complicated process.* My parents are in their seventies and sixties and my dad has been having health problems.

I fear that if something was to happen *to my dad then it might put the family into a position where we had to choose emergency housing for Lisa rather than what would be best suited for her.* I am trying to help to move things forward because *if we keep going at the current pace I worry that it might be five years down the line and if you make it five years rather than two years the likelihood of something happening to one or both of my parents increases dramatically.*

Transition into supported accommodation

It's been talked about for several years but I guess it has really been first talked about seriously probably just over a year ago. Almost every time we see each other that is one of our main talking points, how it has progressed and unfortunately most of the time it has not progressed.

We had one meeting at home with the social worker and Lisa's carers but not much seemed to happen afterwards. It would be very important for Lisa to have 24 hour onsite care *because she has a mental age of one and three quarters and also has epilepsy which is a big concern for my mum. The social worker sort of agreed that that was a criteria that you certainly would want 24 hour care however councils are usually reluctant to provide it, because of the obviously big cost.* So my mum suggested for Lisa to share a house with her two friends so they could share funding for 24 hour care.

My mum has been looking at different options for Lisa including buying a smaller house just for Lisa or maybe for two out of the three people or building a house in their garden. My parents are looking for security for Lisa because the option of renting a property will not guarantee continuity. *It often takes her quite a while like a year or two to settle into a routine but once she settles into it, it becomes quite rigid so while there might be an initial very difficult transition we would like to not have to do it again at a later date*

Ideal scenario

Ideally I would like Lisa to move into a suitable flat or house with her two friends. *Lisa knows them well but also because Lisa, being a social creature, would probably benefit from having not just one family visit her on a regular basis but also these other families whom she also knows and has interacted with and has seen in the past and who know Lisa and who know of Lisa's needs. There have certainly been discussions with the other families about how this could be made possible. I worry one percent that it might not be the right thing for her friend who uses a wheelchair. If Lisa doesn't want to do something she will walk away from you whereas if Lisa was bugging her friend, her friend would not be able to walk away from Lisa.*

I would like to see her carry on through the transition phase at least with some of the carers she has now and who she knows well. Obviously no one is going to stay on forever but it would be nice if not everyone changed at once really.

Barriers to the transition processs:

1. Crisis-driven practice

I feel that because Lisa is in a house with carers just now there is not a great deal of urgency and the council would probably rather that continued. *I feel that they would rather have Lisa on that condition rather than on their financial books as a burden to them and so there is less emphasis for them to move on.*

2. Cost of providing 24hour care

Providing 24hour care costs a lot of money. *They currently have various preliminary options to use technology instead. They might have sensors in the bed that would detect a fit and that would ring an alarm in a control centre and then they send someone out. But Lisa might not be willing to stay in a bed, she might get out of it and then if she had a fit on the floor or somewhere where there was not a sensor then that might cause problems. Lisa could possibly bounce to the floor and then have a fit and that can be an issue.*

3. Housing shortage

With the housing shortage being as it is just now the council seemed to suggest that a four bedroom flat which is what the three of them would need plus for a carer would be very difficult to find just because they are in demand by families.

4. Lack of information and inflexibility

They have not provided any information and my parents needed to contact relevant professionals to find out information themselves. I don't think they really appreciated or provided support to my parents. Additionally, there has always been a sort of great negativity towards some of the ideas of my parents like sharing the house with a second or third person. If Lisa and the others do not get along then it puts the house in a difficult spot. That is definitely a potential complication and their job is to make us aware of the complications and I definitely appreciate that but at the same time there has been no appreciation by them of the benefits of it. Money is tight for the council I do appreciate that but at the same time I feel that when they got these options that might potentially be a benefit for them as well they don't seem to consider shared accommodation as an alternative.

Future

I worry for my parents. I worry that Lisa won't get the best opportunity that she maybe could because the council are dragging their feet and maybe my parents are not aware of the opportunities they might be entitled to. I am quite worried it might all end up in a bit of an emergency situation.

Thoughts on current service provision

I think inclusion in the community is very important. I think that is a positive thing and one thing I like about the café at her current day service is that it is open to the public and quite a lot of the public use it and come in and interact with the disabled adults. But local authorities seem to have limited budgets and I think it would be beneficial for them to consider more service provision that offers shared accommodation. For example, right outside my flat they developed a sort of care home, for want of a better word, for disabled adults. And in essence I think the idea of it is actually quite good. They all get their own room, they all have their own toilet facilities, they all have their own en-suite. You could build a group of small houses, three or four bungalows, where people can live together and be part of the local community and share their staff. It would have to be under scrutiny so you don't end up with the institutional problems that you had before but I think in general with proper training and with scrutiny that could easily be made to work.

I think the vast majority of the disabled support network would probably already recognise the benefit of such a model cause they are already using it to greater or lesser extent for example most respite services are residential.

Summary for participant in study three

Interview summary (written from a first person account with direct quotes from the interviews in *italics*)

Own background

I initially lived in the community for two years, then left for three years but returned around two years ago. I am a medical professional by training. I supported the house where John lived and I was involved in supporting his end of life care.

Description of transitions into older age

It seems to be a process of *gradual slowing down. I mean everyone is still very engaged in workshops but just slightly less energy to do things.*

It can be very difficult to know if changes in behaviour are connected to aging when people have difficulties to communicate. It can be *tricky to really try and figure out* because someone might not be able to articulate their needs or choices. In some cases people also take medication that might make them more tired so you do not always know what it is when someone starts to be less engaged in activities.

How to involve people

It is just quite hard to tease out whether someone does want a change or whether it is just too much or again how does the medication play in. I think often it is a verbal discussion, a choice or just trying out a change. I would like to involve people a bit more. For example, with one man it is a lot easier for him to express things nonverbally, sort of showing you what he wants to do. For him to just go when he needs, a bit of a break and space and then for him to come back and to understand that it isn't just him being bored or lazy. It is just that he needs a bit of space.

I can find it very hard to try and involve people as much as possible in the decision. You feel sometimes that you are making decisions for people or influencing their choice quite a bit. I guess I haven't quite figured out how to do that in other nonverbal ways. A lot of the time you try something out and then you see how people respond and how happy they are with the change.

It becomes difficult towards the end of life, when people are less and less able to communicate. *I think in hindsight it would have been nice to know what John would have thought of those things before we reached the point where he could not decide but that is a big thing.* I mean how would you discuss that with someone now. *I am not sure how to really make sure that you got some of these views right and get them involved in those decisions.*

With some people you get the sense that they are able to understand a lot but are not able to express themselves. Assessing capacity can be difficult. *I mean with most it comes up with dental treatment yeah like medical treatment and then they have a capacity assessment but just on the spot and usually the dentist opts to treat in best interest.*

Decisions that need to be made

Decisions we need to make with and for people relate to medicine, treatment, choices around food and daily activities. I often feel that people are able to be involved in daily decision-making around food or activities. *I guess with the bigger decisions often you just end up making that decision for him in his best interests.*

In John's case we needed to make a lot of medical decisions around his care towards the end of his life. *We wouldn't transfer him with his legs anymore, then to use a hoist, medication, decisions about withdrawing certain treatments like medicines that were becoming difficult for him to swallow or you know that there was more, he was not getting so much benefit from the medicine anymore and it was more of a problem to take the medicines. And towards the end then it was the decision with the GP as to sort of resuscitation and that kind of thing.*

I think we tried to make the decisions that would be have been in his best interest. But I think we made it at a point when it was really clear, like that he was really nearing the end of life and I think it would have been harder to make that any earlier. There just seemed to be a very clear point, it was funny how clear that was, now we just really need to make John comfortable and do everything that we can. Rather than fighting to have more and more time to just really to make the time we have got really good. Yeah so I think in terms of resuscitation and withdrawing treatment it would have been very hard to make those decisions any earlier than we did.

All healthcare professionals involved were very helpful and it felt like we made decisions together.

Working with families

Guardianship becomes a topic that we talk to families about. Parents might feel that due to their own age it becomes harder for them to be involved. *As people's parents get older or pass away yeah I think that is quite a difficult process to go through with people.* Siblings often take on important roles.

We try and involve family members as much as possible through regular phone calls or inviting people to visit. *I feel very much that they have a lot of trust in what we are saying and I feel a lot of responsibility there.*

Working with professionals

In John's case I experienced nurses and other health professionals as very supportive. Working with his social work team was more difficult. Because he is originally from England his social work team is still based there. Due to the distance they did not visit regularly. *We started asking for a review in November and then it was really, really difficult to organise for them to visit John. It wasn't till February that they were able to come. I mean they were happy to agree to give us the funds we needed to be able to keep John here but at that point it was, I mean we put most of the things in place that we needed I think. I did feel like I did have to push quite a lot on the phone with the social worker but in the end they did agree eight hours extra funding but by the time they then agreed John had already deteriorated even more and needed two people all the time to transfer. So by the time they agreed the extra eight hours actually what we*

needed was double that. So you are always kind of catching up I don't know it is I don't know how it could have been different.

Barriers to best practice

In the end health services provided a lot of the end of life care because it was difficult for us to recruit staff. There was no interest. All the local companies were either full or don't cover this area because we are so rural it is quite difficult. I imagine it happens a lot that healthcare services need to step in because of how difficult it was to find care through the social sector.

I think it would have been better for John if he could have had his brother close by. I guess a lot of people move quite far distances to come and live in our community.

Strength of the community: Being a home and having connections

Most people live here for many years and the community becomes their home. John lived here for over thirty years. People here just knew him so well and I think that makes it easier, even when his dementia was so advanced, to really make a connection. I think it is still hard to, hard to truly get somebody's views on certain decisions but I think it does make a huge difference. You are kind of surrounded by people who have very established relationships.

I also felt very supported by the community. There were so many other people with a strong connection to John, so many people who also cared for him. It felt very shared.

Describing the process of dying

John lost most of his words over the last couple of months but there would be just this moments where he would suddenly be very lucid, pick out people in photos, call out people's names, sing along to a song that he knew. But those moments would be more and more spaced out and in the end it was really hard to make decisions. In the end the only real way he expressed himself was by showing pain.

After John died that was incredible. I don't even know how you deal with that on your own. It was really like a lot of people stepped in and did a lot of the organisational things that I wouldn't have been able to think of at that point.

The community was very involved in making the funeral arrangements. Registering the death and sorting out his finances. We communicated closely with his brother. We had a celebration of his life in the hall and then a burial in England, organised by his brother.

Appendix 9: Example of summary of research findings for participants

Summary of research findings for participants study one

My research involved three young people, their family members and professionals who were involved with them at the time of transition between school and adult placements. The professionals included teachers, health and social work professionals and higher management within the Local Authorities that are represented in this study. Names have been changed and any identifiable information has been removed. I will give a short introduction to the three young people and then discuss the main themes that I identified from my work.

The findings are based on data that was collected using interviews with parents and professionals, case specific documents and by spending time with young people at school and/or the adult setting.

A short description of the three young people: Tom, Emma and Peter

Tom: Tom was sixteen years old when I started my study. Tom has autism and severe learning disabilities. Caring for Tom is very complex as he displays high levels of behavior that challenges. Tom has two more years at school, but as he is about to turn seventeen he is approaching a transition from respite services for children, to respite services for adults. This will result in a significant reduction in respite days. Tom's parents want Tom to continue to live with them but feel that they need sufficient support and respite to be able to do so. There is only one adult respite service in the local authority that is able to support Tom and that offers overnight stays. As a place becomes available at the service for summer, his parents take the decision for him to leave school one year earlier than had been planned. The service seems able to meet Tom's needs but in an ideal scenario he would have more time there. The cut in respite is a big concern for his family, who worry how it will affect both Tom and the whole family,

Emma: Emma is seventeen years old and in her last year of school. Emma has a diagnosis of autism and severe learning disabilities. She depends on other people to prompt her, and requires a lot of help and support, even though she is physically very able. Emma's parents feel that they are approaching an age where they would like Emma to start living outwith the family home. This has been discussed with her transition social worker but does not seem to be an option just now. Exploring day service options, her parents feel that Emma needs a five-day service. They would like Emma to go to a local day service that offers workshop-based activities. To make it possible to fund the day service for five days, her respite allocation is reduced. While the family thought initially they could cope with it, they are finding it increasingly difficult to manage with less respite. The wish for supported accommodation - a place for Emma to 'settle' - remains the main concern for her family.

Peter: Peter has autism and severe learning disabilities. Peter is physically very able but similarly to Emma, Peter needs other people to prompt him for most day-to-day activities. He has a close relationship to his brother who also has a diagnosis of autism and severe learning disabilities.

Peter's family live in a rural area of Scotland. Having two children with high support needs was challenging for the family living in a rural area with few local resources. When the family were looking for a secondary school placement for their sons, they became aware of a school offering residential placements; Peter and his brother went to live there during term time. The family were very happy with the residential community setting, and want a similar placement for Peter and his brother, now that they are reaching adulthood. The primary concern for Peter's parents is finding somewhere that their two sons can continue to live together. After one service rescinds their initial offer of two placements, his parents apply to a residential community for young adults three hours drive away; a place is offered to both boys. The adult community offers placements for young adults up to the age of 25 and his mother is anticipating to start planning for the next transition very soon.

For all three young people, their parents visited a variety of services for adults and parents gathered information. Information about services came from other parents, social work and parents doing their own research. Parents based their choices on which service appeared to be best able to offer their children a good quality of life. Services being able to meet their children's needs, cater for their interests and keep them safe were priorities. In Peter's case this, rather than proximity to their home, was of primary importance to his parents. Similarly, in Tom's and Emma's case finding 'the right service' was the main concern.

Themes

All the information was read in great detail. Similarities and differences between the experiences of the transitions of the three young people were explored. Themes, referring to experiences, main points and views that were highlighted by those involved, were developed by interpreting what people had said and what I had seen in person and read in documents. Across all of the information gathered, it was evident that the transition of a young person with an intellectual disability into adulthood is a complex process. Strikingly, families seemed to be alone in their worries for the long-term future of the young people.

1. Involvement of young people

Participants felt that young people had very little involvement in the transition process, although (for participants) this may be because choice was conceptualised (in general) as actively verbalising choices, which was not possible for the young people. However, from the data, it can be argued that there was involvement of the young people in their transition because they expressed how they felt in different environments and communicated their needs through their behaviour, for example through their engagement or non-engagement in activities or expression of feelings.

Peter's mother: *Peter has gone there because we have chosen for him to go there and his views have to be I guess the views of my husband and I because we are his welfare guardians but then if you are saying was he very much involved in the transition? Yes we took him to see the place and to see how he felt*

2. Two Aspects of Transition: Practical and Organisational

The study suggests that transition is not a single process, incorporating both decisions about placement and the actual practicalities of transition. The degree and nature of involvement of the young person differs between these, and the influence of the other people and other systems also differs. These two elements were described as: (1) Supporting the young person with the actual move from school to a new service and (2) the decision-making process on an organisational level.

- **Practical Transition**

The practical transition was described as very positive for all three young people, with good communication and sharing of practice of all stakeholders.

Tom's mother: *The school were excellent. They went there quite a lot leading up to it. His speech therapist certainly was involved making plans for how he communicates.*

Peter's mother: *So they worked very much with us in what we thought the boys could achieve. And it was all very flexible. So if the boys were, they knew it was very important for example that the boys would stay together.*

The move to the new setting was described as positive and all young people seemed to be doing well considering that the transition involved a major change in environment and routine. Young people were described as participating in activities, following their new routines and positively interacting with staff.

Emma's mother: *We are just delighted with (the service). Just absolutely over the moon. It is such a nice place.*

Peter's social worker: *They had a pretty good transition I think, they seemed to settle very well into the (new place), surprisingly well actually.*

Tom's adult service: *There was moments where he was smiling and moment where he has been laughing and he has been engaging with staff.*

While the practical transition was described as very positive, a number of barriers and difficulties were identified in the wider decision-making process. Barriers within the organisational realm related to limits within amounts of budgets and

paucity of services.

- **Organisational barriers**

Parents and professionals seemed to have positive relationships and problems did not seem to relate to the personal relationships between stakeholders but to limitations that resulted from wider political issues. There was a sense that all stakeholders were trying their best within a climate of funding cuts and paucity of services.

Tom's social worker: *You know we might have limited resources and what Tom can access just based on his needs or based on the provision within the city but it is still about you know within these limits it's about making sure we have what's best for Tom at all times. And I hope that is what we have done.*

Paucity of services was referred to by participants in a number of ways: Parents and professionals described a lack of local services for young people with high dependency and complex needs and existing services seemed to operate at full capacity. Additionally, in Emma and Tom's case, parents felt there was a mismatch between the amount of support they and their children needed and what was available to them.

It seemed that everyone, from parents to social workers and local authority management, felt that their possibilities were limited by strategy and budget decisions that were made 'higher' and which they were unable to influence. A number of participants felt that there was less importance given to services for adults, in comparison to services for children.

Manager LA 1: *The budgets are made in Westminster or they are made down in Holyrood. (...) If it continues to decrease it will present us with, well it already is presenting us with real challenges going forward. I don't have the answer to that question yet.*

Tom's mother: *It just seems people can make legislation but actually what difference does it make to those at the core? Not very much.*

Emma's social worker: *There is a change you know we are more in a corporate sort of world and environment and it is if you are an old school social worker like me it is really not great. (...) if you feel like you are fighting a system (...)*

Peter's adult service: *The difference between the reality and what is being presented and what is said has never been as wide as it is now, ever since I am involved in this work, and that is forever. So I have never known a time like this. I think it is really, really desperate and I think personally I just don't know anymore I can no longer point to people and say it's the fault of the director of social work or the director of here or this person or that person. It is the whole system that needs to be changed.*

In Tom's and Emma's case limits within available budgets for each young person appeared to go against a person-centred approach. Mothers and other

professionals felt that trying to save money by cutting respite provision and trying to fit young people into a 'fixed' budget, was short-term thinking with the risk of creating crises.

Tom's mother: *I think there is this ridiculous scenario of the fact that if we said right let him go to a flat you are talking upwards of 200 000 pounds a year to fund that. Whereas we are quite happy for him to stay at home and go to [Adult Service X] everyday but we still feel we need more respite. It is not always joint-up thinking is it? Some children do not fit into the budgetary slot that you give them and Tom is unfortunately one of them. I didn't feel there was any room for maneuver at all. Sadly.*

Emma's social worker: *(...) the needs are so different and they are all getting the £26K and I, I find that difficult. I find that really difficult. You know you are substantial or critical but there is a huge, you know, it is such a broad spectrum and so that, that really needs looking at.*

Parents experienced negotiating budgets and agreeing on care packages as stressful and as a 'fight for their children'.

Emma's mother: *I mean it is not about the money it is about the principle I think. But every little step brings more problems with it, if you know what I mean, because it is just another anxiety and they know that, so they know that people will get fed up with fighting.*

Peter's mother: *I mean it is not easy when your phone calls don't get answered or emails. You have to appreciate that you are in a queue. But as I say we are fighting for our children, someone else fighting for their children.*

In all three cases, parents started to think about and plan the transition between three to two years in advance. There was little information and support available from others at those early stages and parents relied on themselves to find out about available places.

Peter's mother: *But you know as I say you have to go and find it. As I said we were not offered [the residential school placement], like we were not offered [the second primary school] and I think [Peter's father] and I were very concerned very early on that we better raise transitions cause we don't know what is out there.*

In all three cases initiative by parents led the process. This raises question of what happens in cases where parents are unable to do so.

3. Differences between the three transitions

Across the three transitions differences were identified in relation to service provision in the two local authority areas, the transition process and young people's needs.

Tom and Emma lived in a local authority with a relatively greater choice of services, yet there appeared to be a lack of services for those with complex health care needs and challenging behavior.

Tom's social worker: *There is a lack of support services for people with complex behavioural needs absolutely. Complex personal care needs absolutely. So we, every year, we have these difficulties and I think what we are actually lucky in [our local authority] in that we have quite a high number of services compared to some other local authorities. Even with that being said, there are gaps without a doubt.*

Tom's mother: *We have been to look at quite a few places and I have to say that most of them for Tom were very unsuitable. (...) It is just the fact that the more you go down the line the more you realise quite how disabled your child is. Profoundly disabled in all areas in that there is not much out there that is going to help. It is a difficult, difficult time, because the reality sinks in a bit more. I have always known that, don't get me wrong, but the reality of how life is gonna be hits you.*

For Emma there seemed to be more choices, but her parents experienced a lack of 'meaningful' services, as they did not want a 'babysitting' service. Favoured services were more expensive and were not covered by the allocated budget.

Both Tom and Emma transitioned to adult respite service on their 17th birthday, leading to difficulties as families were faced with two disparate transitions (from school to adult services, and from child to adult respite). Likewise, both families experienced a decrease in support within adult services, with Tom's family experiencing a significant drop. A decrease of support in adult services, while needs of young people remained high, was incomprehensible for parents.

Due to a lack of local services, Peter and his brother accessed schools further away from their family home during their school years, moving to a residential secondary school. The family chose a similar set up within adult services. Peter's mother did not experience getting funding as difficult. This seemed to be related to a residential placement being more cost effective than 24 hour care in a flat, while a lack of local services and available local places also played a part.

Peter's social worker: *There wasn't other identified supported accommodation in terms of vacancies that we had that both young men could access, so we just didn't have anything on the local level that was really suitable or appropriate.*

Within the local authority, differently to the previous two cases, there is no transition social work team. Children and adult social work, work together to plan the transition process.

4. Worries about the long term future

All families described anxieties in relation to standard of care of services and the need for trustworthy staff. For the future, Tom's mother feels that with the right support they would like Tom to continue to go to the adult service for day and respite and to live at home.

Tom's mother: *I am hoping he can stay there for many years. I am hoping he can stay with us until we are too old and too decrepit to look after him any more.*

Both Peter's and Emma's parents want to find a safe and stimulating placement outwith the family for the long-term future. Stakeholders in Emma's case all described that living with other young people might be better for Emma than living in her own flat. Her parents are concerned that applying for supported accommodation will mean that Emma won't be able to access her day service any longer.

Emma's mother: *(...) they have cut their day service so they are really just sitting in the house, twiddling their thumbs with a carer and unless you have a fantastic carer these people are just left to vegetate.*

Similarly, Peter's mother does not see him living in a flat but continues to want a residential community placement, feeling that living in a flat would isolate Peter.

Peter's mother: *I think that living in a flat in a city centre will not suit Peter or his brother. You know they are both still very vulnerable young people and I think you know they need to be with individuals that are trained and they can trust, and it is reciprocal you know the boys continue to be treated with dignity and respect despite their limitations.*

Parents were the only ones who explicitly talked about transition in terms of the long-term future, planning for a time when they would not be able to look after or advocate on behalf of their children any longer.

Emma's father: *She eventually will have to, we are going to die at some stage and if you, we are not looking forward to that bit but (...) the point is she is going to have to be in a place that wants her and where we are satisfied that she is going to be looked after properly.*

Tom's mother: *What will happen when we are dead is my main concern. Who will look after him? Will he be happy? Will he have a fulfilled life? And he is very vulnerable when someone hurts him he can't tell us.*

There appeared to be a mismatch between the understanding of the transition as an event from one service to another within the organisational context and

families asking for a whole life-course understanding. The service manager in Peter's local authority had a similar view and believed that a life course perspective could improve practice.

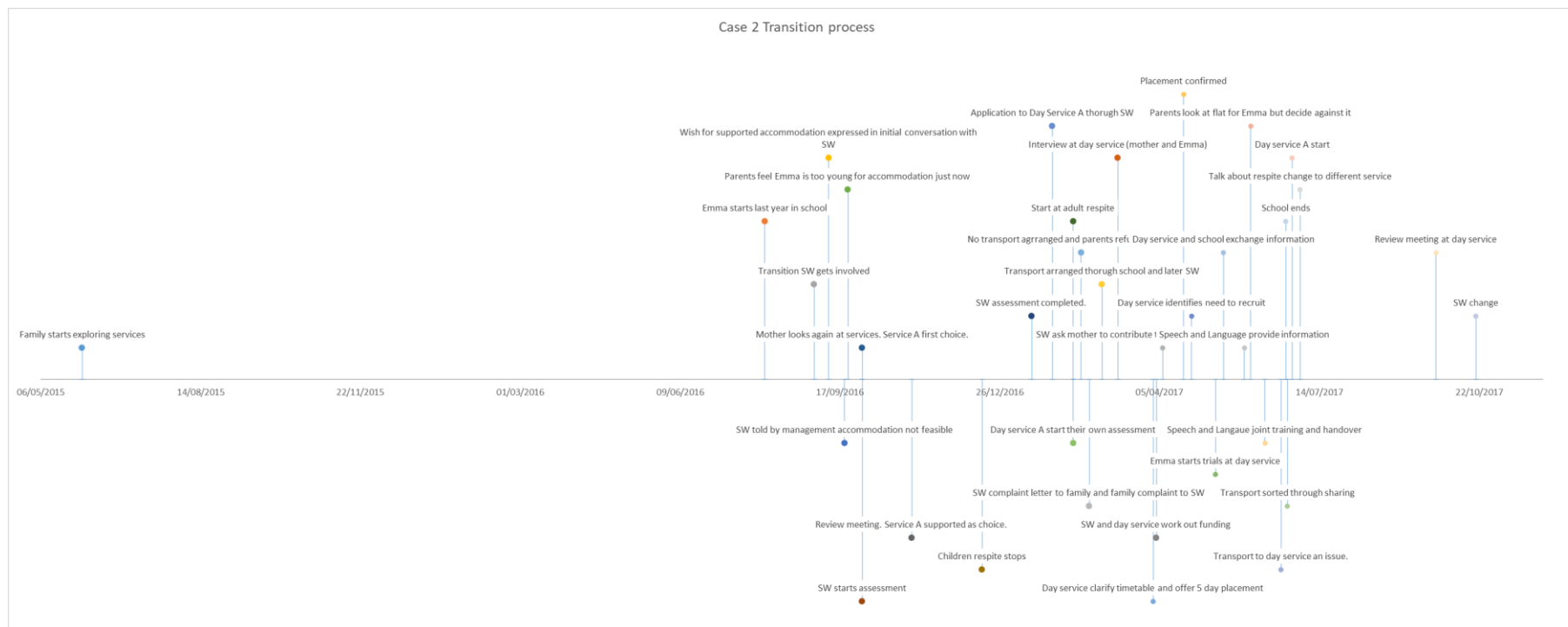
LA Manager 2: *I am not a great fan of the concept of transitions. (...) I don't think families find it an overly helpful (...). And they shouldn't be creating scenarios like transitions because it creates an awful lot of barriers in terms of practice, approach, finance and a lot of confusion and anxiety for families. (...) I would take the simple view of somebody with a disability requires a service from social work and the NHS from birth to death.*

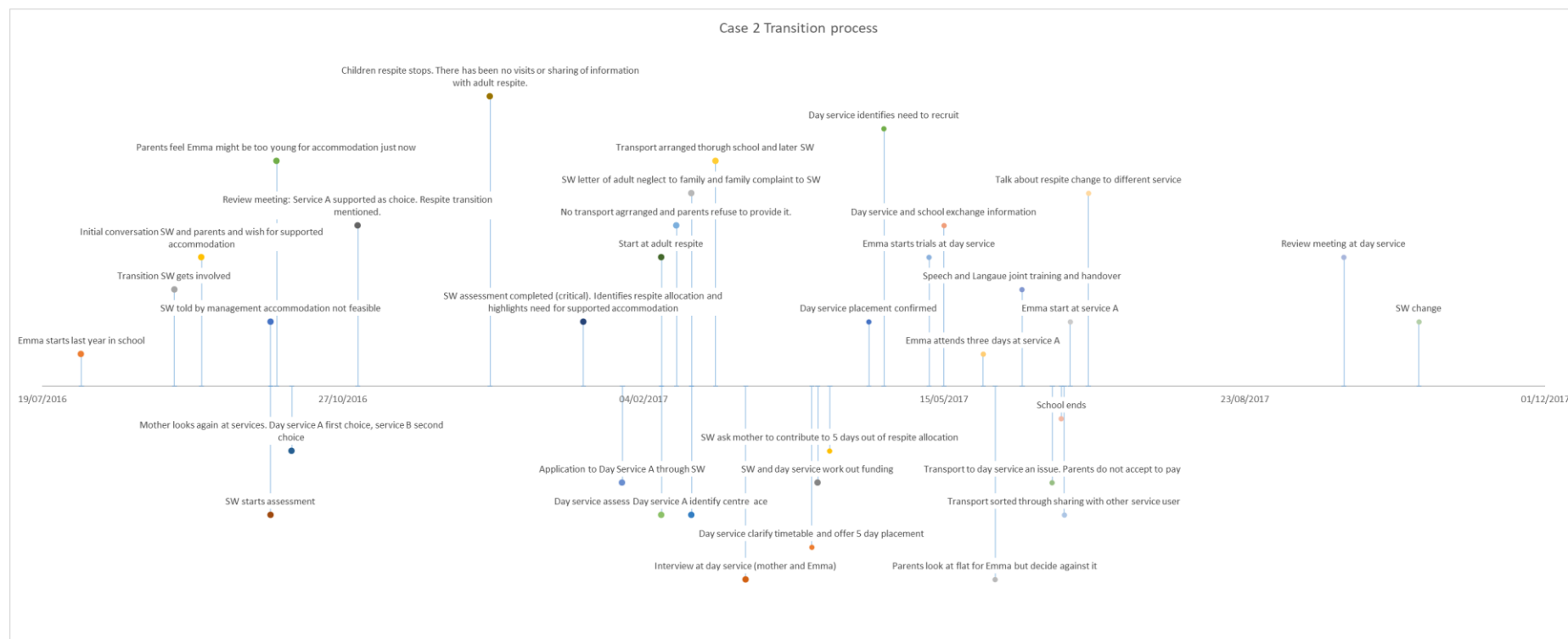
Summary

The transition posed questions about the involvement of young people in the decision-making process. In particular, how to understand the concept of adulthood when young people continue to depend on others across the course of their lives. While the practical aspects of the transitions were described as positive, barriers and limits were identified in the wider organizational context. What stood out in the transitions of all three young people was that, after the transitions, many questions and concerns about the future for their children remained for parents. Tom and Emma's parents worried about being able to cope with less respite, and Emma and Peter's parents were already anticipating the next transition to a more permanent adult placement for their children. In general, all parents were concerned about their children's long-term future; this was one of the strongest themes. It seemed that there was a mismatch between parents and professionals, with professionals mostly viewing the transition as a one-off event, while parents asked for an understanding of their children's ongoing need for support. The greatest worry of parents related to what would happen to their children once they reached a point where they were unable to continue to be strong advocates for their children.

Appendix 10: Example of Excel timelines

Timelines study one case two





Appendix 11: Search retrieval protocol systematic review

My research question:	What is known about the transition of young people with severe or profound ID who are transitioning to adult services?			
Places to search for information:	PsycInfo, Social Services Abstracts, CINAHL Plus, Sociological Abstracts, ERIC, Social Care Online, ASSIA, Dissertation and Theses Global, Embase, MEDLINE			
List of sources searched:	Date of search	Search strategy used, including any limits	Total number of results found	Comments
PsycINFO <1806 to January Week 1 2017 (full text)	08.01.2017 Repeated search 10.10.2017 starting 1 st January to 10.10.2017	(Intellectual or learning or development* or neurodevelopment* or cognitive or mental) and (handicap* or disab* or difficult* or impairment* or	4003; After exporting to EndNote and screening for duplicates 3856 items left. Exported 3856 into EndNote “allresults1”	2 nd search: 215 items identified and added to folder secondsearch = 215

		deficien* or incapacit* or delay or disorder* or retard*) AND (transition or "adult service*" or adulthood or "adult life" or "post school" or "leaving school") AND (Profound or Complex or Multiple or Severe or Dual or Serious)		
(Search terms 1 and 2 limited to abstracts) Social Services Abstracts	10.01.2017 Search repeated 10.10.2017	(Intellectual or learning or development* or neurodevelopment* or	147 (before duplicates removed) 139 exported	Second search: 3 results added to secondsearch = 3

CINAHL Plus		cognitive or mental) and (handicap* or disab* or difficult* or impairment* or deficien* or incapacit* or delay or disorder* or retard*) AND (transition or "adult service*" or adulthood or "adult life" or "post school" or "leaving school")	into EndNote "allresults2"	Not repeated for CINAHL
Sociological Abstracts		AND (Profound or Complex or Multiple or Severe or Dual or Serious)	2714 (exported into EndNote and added to previous results) screening for duplicates removed 27 duplicates 384 (exported into EndNote and added to previous results) screening for duplicates removed 135 duplicates	3 results identified and added to secondsearch. Screening for duplicates removed 2 duplicates = 1
ERIC			871 (exported into EndNote and added to previous results) screening for duplicated removed 279 duplicates	3 results identified and added to secondsearch. Screening for duplicates removed 3 duplicates = 0

Social Care Online			2 (exported into EndNote and added to previous results) screening for duplicates. No duplicates	No results identified for second search
ASSIA			480 (exported into EndNote and added to previous results) screening for duplicates removed 216 duplicates.	39 results identified and added to secondsearch. Screening for duplicates removed 38 duplicates = 1
ProQuest Dissertations & Theses Global			2148 (exported into EndNote and added to previous results) screening for duplicates removed 124 duplicates. Within EndNote folder allresults2 now 5957	45 results identified and added to secondsearch. Screening for duplicates removed 17 duplicates. = 28

			items (6738 results minus 781 duplicates)	
Embase 1980 to 2017 week 1 and Medline 1946 to Dec, 2016 (Search terms 1 and 2 limited to abstracts)	11.01.2017	(Intellectual or learning or development* or neurodevelopment* or cognitive or mental) and (handicap* or disab* or difficult* or impairment* or deficien* or incapacit* or delay or disorder* or retard*) AND (transition or "adult service*" or adulthood or "post school") AND (Profound or Multiple or Severe)	8664 (exported into EndNote and added to previous results) screening for duplicates removed 1232 duplicates. In folder allresults2 now 13389 records (5957 plus (8664 minus 1232)) On 11.01 added the 3856 PsychInfo results from folder allresults1 to allresults2 Screening	10.10.2017 Second search identified 539 items. Screening for duplicates removed 84 duplicates = 446 All in all 694 items identified resulting in 15940 records that were included in the review

			for duplicates removed 1999 duplicates. In EndNote folder: allresults2 now 15246 items	

Adding together all results and deducting duplicates results in 15 940 items.

Appendix 12: Example pages of full-text review protocol systematic review

Stage 3 Inclusion/Exclusion Review (Full text)

Table 3: Inclusion criteria

Criteria	Justification
From earliest available records to 2016	As this is an under researched topic the search will be kept open by not applying a time limitation. However, this might be reviewed should the search identify too many irrelevant old papers.
1. Examines the process of transition, facilitators and barriers	The examination of the transition process and possible facilitators and barriers must be part of the findings of the study. However, as this is a relatively under researched topic studies that do describe the process and facilitators and barriers but have a different primary aim will still be included. This might include studies that focus on parental experiences, quality of life or person-centred planning. The research will also include all studies that focus on the process, even if this is based on different perspectives, such as professionals, family members or young people themselves. As the aim of the systematic review is to include an ecological perspective (if possible) different perspectives will be valuable.
2. Relates to people with profound ID aged between 13 and 26	The age range is based on current policy guidelines that recommend that some transitions are planned years before the young person's actual transition, while the age for young people to stay within their current setting and to be eligible for transition support was extended to 25 years. Profound ID will be defined in accordance to ICD-10 and DSM-5 and describe individuals who are in need of substantial or constant supervision and support and reliance upon others to make decisions on behalf of the individual. Findings need to be discussed in relation to profound ID in cases where sample includes a range of young people with different disabilities.
3. Published in the English language	Due to time limitations and feasibility only studies published in the English language will be included.
4. Original qualitative or quantitative data	The researcher anticipates that most studies will use qualitative data, as this appears most appropriate to answer the research questions. Yet, to not exclude any studies quantitative data and mixed-method studies will also be considered if they meet the inclusion criteria.

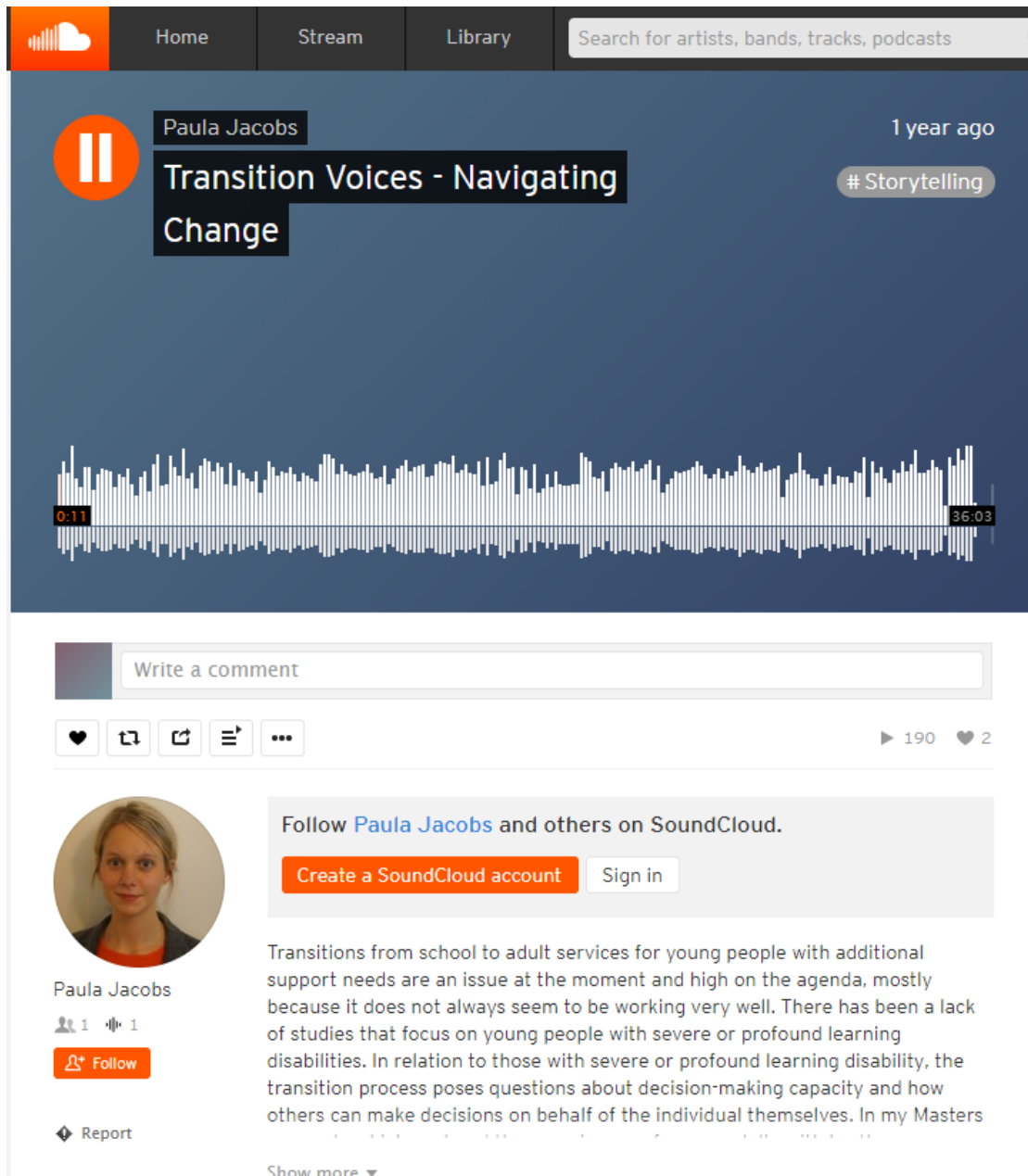
Source	Discussion	Decision
Models To Improve Service Delivery. Chapter 8 Effective Transition Starr Silver, Ph.D.	Based on a National Adolescent and Child Treatment Study. Focus on children with emotional disturbance (participants) and transition. Interviews conducted with young adults and with one of their parents. Exclude as participants do not include those with profound ID.	4 Exclude: Not including profound ID
Kentucky Services to Children Who Are Deaf-Blind, 1995-1999.	Report that evaluates outcomes of project to improve services for children who are deaf-blind and their families. Most evaluations do not meet inclusion criteria such as interventions around family support and providing technical assistance. Yet, one intervention focused on transition and within that some on transition to adulthood. Issue of lack of individual's characteristics. Deaf-blind and multiple disabilities is mentioned at one point. Unclear if this includes profound ID. The only relevant sentence in whole report states: "At the end of this grant we noted that 58% of the students on our census are transition age. In addition, 72% of these students are reported under our state's Part B Child Count as having multiple disabilities. This indicates that a large number of the students we serve will require transition services and that their transition needs may be complex." This is overall a report on the project and not a research study.	2 and 3 Exclude: Not original research study and not discussing profound ID within findings
Al-Jazzaf, Abrar M. (2012).	PhD thesis. Surveys exploring	2 Exclude: Not discussing

	and so forth. No section on methodology or analysis Mentions Iowa census data. Data collected in terms of additional disabilities to deaf-blindness does include ASD, emotional disturbance, speech impairment and also LD but without different levels. Report includes questionnaires used and material and short report on recommendations. Transition in this short bit relating to transition across lifespan and especially in relation to inclusion. Deaf-blind not necessarily profound ID. Transition to adult services not focus	school to adult services focus Part of series of evaluation of projects for deaf-blind services across different states of America.
McDonald et al (1992). Interagency planning for students with severe disabilities: A two-year pilot project.	Transition planning project at school with 7 students described as severe developmental disability and their parents, teachers and adult service worker and facilitator. A planning process model was developed and piloted with the participants over two years resulting in six positive adult placements. A transition planning process was developed during a workshop involving all of the major stakeholders. This transition planning process was piloted over a two-year period in the two school systems with the <u>students and their families, their teachers, and an adult client services worker.</u> YP described as: between 18 and 19. 4 verbal	Not enough information on young people. Otherwise this would meet criteria. Emailed author. 4 Author answer: Not including severe/profound ID

	appears to also include moderate ID. Any cases of profound ID are not discussed or highlighted separately.	
Florian et al (2000). What happens after the age of 14? Mapping transitions for pupils with profound and complex learning difficulties Part of Cambridge Byers study	Report of part of three part national survey of provision for pupils above 14 with profound and complex learning difficulties. Connected to earlier article Dee and Byers. Learning difficulties defined as: profound cognitive impairment or learning difficulty and complex aggregation in more than one area of lives. Also consulted the received publications from author and definition fits own definition. Furthermore mentions: extreme demands upon services, exceptional communication difficulties and extensive and ongoing support needs. Questionnaires on service provision sent special schools in England and Wales with focus on destination of YP with profound LD (as defined by study) within next academic year. All YP aged 14 and above. Specific focus on 17% who moved from school to "other" and questionnaire asked open ended details on provision after school	Include
Gray et al (2014). Outcomes in young adulthood: Are we achieving community participation and inclusion?	Investigating changes in living arrangements and daytime activities. Also looking at parental mental health. Follow up study looking at YP in Wave 1 (1991) ages between 4 and 19 and later 20 to 38. 536 participants in total = 18 year period. Degree of ID described as mild, moderate and	5: Exclude: not examining transition process

Appendix 13: Publications and research output

1.1 Audioplay Transition Voices – Navigating change available at:
<https://www.ed.ac.uk/health/research/centres/ccri/projects/transition-voices-navigating-change>



1.2 Journal articles

- 1.2.1 Article published in JARID (included with permission from Wiley Publishing)
- 1.2.2 Article published in Disability & Society (included with permission from Routledge Publishing)
- 1.2.3 Article published in International Journal of Social Research Methodology (included with permission from Routledge Publishing)

REVIEW ARTICLE

Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis

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Background: The transition to adulthood has been described as a difficult time in the lives of young people with intellectual disability. There has been little emphasis on young people with severe or profound intellectual disability specifically, even though their pathways may differ, due to greater support needs across the life course.

Methods: A systematic review was conducted utilising Bronfenbrenner's ecological model to inform framework analysis to synthesise qualitative findings.

Results: Taking an ecological perspective proved valuable. The transition process was described as stressful and barriers were identified across the ecological levels. Parents accounted for the majority of participants in studies, and the needs of young people and their parents emerged as highly interdependent.

Conclusion: Themes reflect the complex nature of the question what adulthood should look like for individuals with severe or profound intellectual disability. There is a lack of involvement of multiple stakeholders and young people themselves within studies.

KEYWORDS

framework analysis, profound intellectual disability, severe intellectual disability, transition

1 | INTRODUCTION

The transition to adulthood for young people with intellectual disabilities has been highlighted as an area of significant importance (Doran, 2011; Foley, Dyke, Girdler, Bourke, & Leonard, 2012; Hardy et al., 2005). In relation to those with severe or profound intellectual disability, the transition process poses questions about decision-making capacity and how others can choose on behalf of the individual themselves (Nind, 2013; Ware, 2004). Studies that examine transitions and involve the person with intellectual disability mostly include participants with mild-to-moderate intellectual disability (Daviso, Denney, Baer, & Flexer, 2011; Foley et al., 2012; Mitchell, 2015), or do not differentiate in their findings between degrees of disability (Pilnick, Clegg, Murphy, & Almack, 2011; Ward, Mallett, Heslop, & Simons, 2003). However, lives and pathways of those with severe or profound intellectual disability may differ due to higher support needs, dependency on others across the life course and

difficulties in accessing further education or achieving employment (Foley et al., 2012; Gauthier-Boudreault, Beaudoin, Gallagher, & Couture, 2017; Hogg, 1999).

1.1 | Aim and scope of the review

The aim of this systematic synthesis was to critically review what is known about the transition to adult services for young people with severe or profound intellectual disabilities. In the case of young adults with severe or profound intellectual disability, decisions regarding future support happen, typically, within the context of multiagency involvement that includes family members, statutory services, such as Education, Health and Social Work, third-sector care providers and others such as advocates (Hardy et al., 2005; Kaehne & Beyer, 2014; Murphy, Clegg, & Almack, 2011). Thus, this review attempted to address the research question from an ecological perspective, to capture not only the

perspectives of family members but also to incorporate findings in relation to the decision-making process of different stakeholders and organisational and cultural influences. To capture the complexity of the transition process and its impact on those involved, the review focused on qualitative studies. Qualitative research is based on a subjective epistemology and attempts to understand meaning and subjective views of phenomena as they occur in a specific context (Saini & Shlonsky, 2012) and provides a means to enhance our understanding of the how and why (Snilstveit, Oliver, & Vojtkova, 2012).

2 | METHODS

2.1 | Inclusion criteria

This review defines transition as the move from school to adult services. When and how transitions take place differs between and within countries. Furthermore, studies within this review were conducted at different points in time, spanning three decades of changing transition policies and service commissioning. Thus, the definition used was broad, including transitions to further education, respite, day and care provision. Although healthcare transitions are considered within some of the included studies, this was not the focus of this review. Essentially, the focus of this review is on young people ending school and being at the threshold to adulthood.

Inclusion criteria were (i) studies published in English, (ii) examining the transition process from school to adult services, (iii) relating to severe or profound intellectual disability and presenting (iv) qualitative data. Severe or profound intellectual disability was defined in accordance to ICD-10, the AAIDD framework and DSM-5, referring to young people who are non-verbal or use very rudimentary forms of communication, who are in need of substantial supervision and support and reliance upon others to make life-changing decision. To ensure that studies were meeting inclusion criteria 3, studies were not solely included on the basis of the diagnostic terms used but based on the description of participants and their needs and abilities. To be included, studies that included a range of young people with differing levels of disabilities were required to differentiate their findings specifically in relation to severe or profound intellectual disability. Many studies reported samples of young people with both autism and severe or profound intellectual disabilities and these were included in the review. Throughout this article, the term parents will be used to refer to all main carers that participated in the studies.

2.2 | Search strategy

The systematic search (see Figure 1) comprised of electronic database searching, review of retrieved articles' reference lists, hand searching, contacting experts within the field and the search of grey literature sources. Databases included were as follows: Ovid, Social Work Abstracts, CINAHL, MEDLINE, PsychInfo, Sociological Abstracts, ERIC, ASSIA, Social Care Institute for Excellence SCIE.

The search terms (Table 1) were applied to each database and combined using AND. Truncations were used to ensure the retrieval of variations of the chosen terms. Full details of the search strategy can be obtained from the first author.

Search Retrieval Protocols were used to document all searches and authors were contacted in cases where important information in relation to inclusion criteria was missing. The search identified two publications based on the same data by the same research team (Gauthier-Boudreault, Gallagher, & Couture, 2017; Gauthier-Boudreault, Couture & Gallagher, 2017). It was found that both publications had significant overlap in the reporting of their results. Thus, one article was excluded as a duplicate (Gauthier-Boudreault, Gallagher, et al., 2017), although its content was closely examined to complement findings of the included article (Gauthier-Boudreault, Couture, et al., 2017).

2.3 | Critical appraisal of included studies

Included studies consisted of eight peer-reviewed journal articles, four academic theses, one book and one government report. Three studies (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Dee & Byers, 2003; DeZonia, 2008) used mixed methods; the current review only synthesizing their qualitative data. There were differences in the studies' methodological quality, with some providing little information about their analysis of qualitative data (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Cox, 2017; Hubert, 1991; Murray, 2007; McIntyre et al., 2004), with one study providing no information (Dee & Byers, 2003). Additionally, two studies provided little to no examples of their data (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Dee & Byers, 2003) to support their interpretations. Both of these studies did not use interviews but described the evaluation and implementation of projects to improve practice. As those two studies focused on collaborative practice, organisational barriers and facilitators, they were still included to enrich an ecological understanding of the subject, albeit with the caveat that they offered very little data that were possible to use within the review. All studies were critically appraised using the guidelines for appraisal of qualitative research developed by the Critical Appraisal Skills Programme (CASP, 2017). The first author reviewed all studies. Eight of the studies were peer reviewed by a second, independent researcher and the appraisal of all studies was discussed within the research team. An overview of studies and the quality assessment can be seen in Tables 2 and 3. Surprisingly, there was no mention of ethical considerations for five of the included studies (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Dee & Byers, 2003; DeZonia, 2008; Hubert, 1991; McIntyre et al, 2004).

2.4 | Data analysis

Framework analysis was the chosen analytic approach to synthesize findings of the 14 included studies. Framework analysis involves the use of an a-priori framework that is suitable for answering the review question, and using it as the basis of coding evidence (Ritchie &

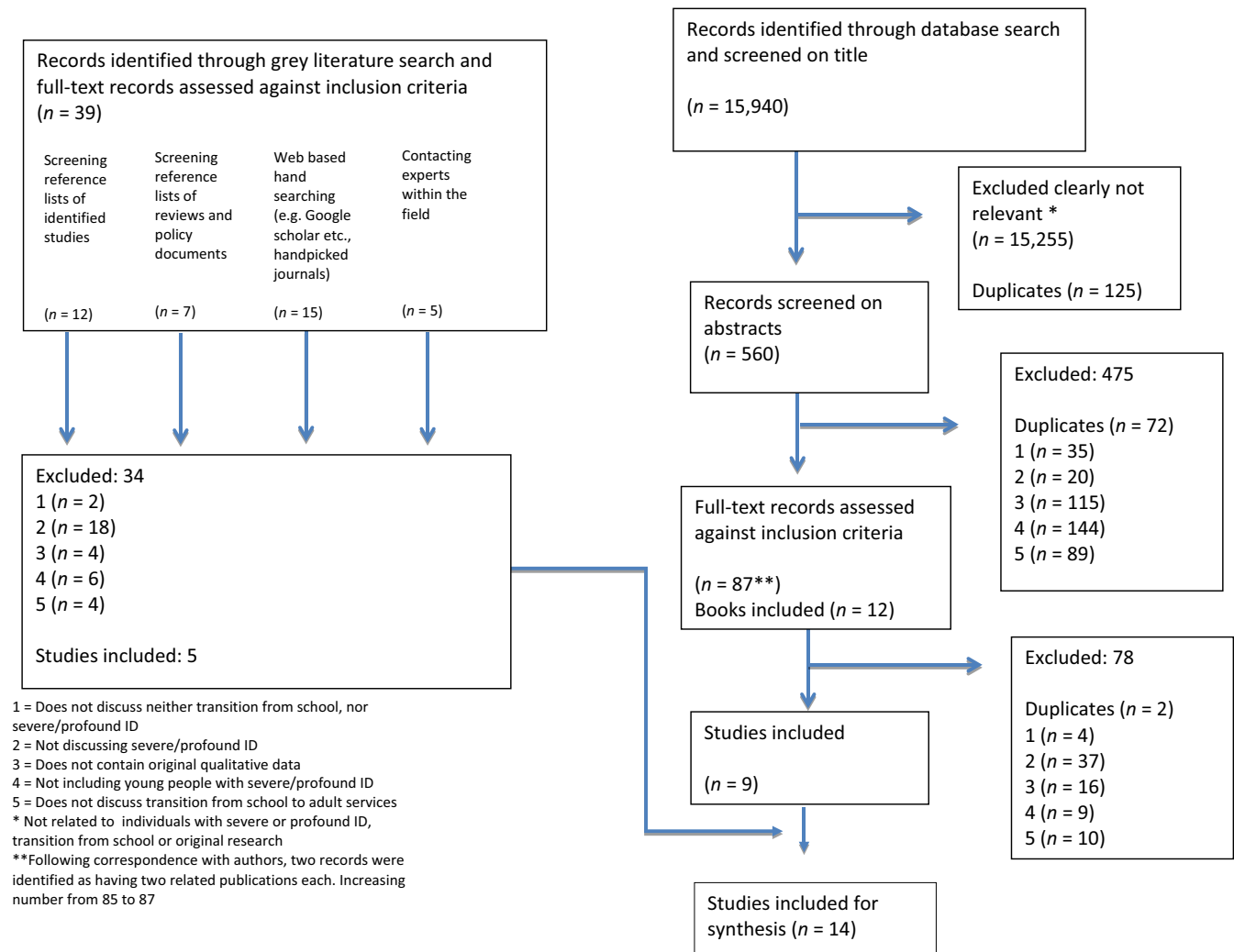


FIGURE 1 Systematic search diagram [Colour figure can be viewed at wileyonlinelibrary.com]

Spencer, 1994). By combining inductive and deductive approaches, it is able to explore predefined themes of concerns that have been developed within the focus of the review, in this case, the decision-making process involving different stakeholders, while remaining receptive to unforeseen and unexpected findings (Carroll, Booth, & Cooper, 2011; Parkinson, Eatough, Holmer, Stapley, & Midgley, 2016; Snilstveit et al., 2012). In the analytic process, the framework might be modified in response to the evidence reported, so that the final product is a revised framework that may include both modified

themes and new themes that were not captured in the initial framework (Ritchie & Spencer, 1994; Stuart, Tansey, & Quayle, 2017).

2.5 | Identifying an ecological framework for data analysis

Initially, the existing literature base was visited in-depth and the selected studies were read carefully. In this case, there was no clear existing framework. In relation to young people with profound and severe intellectual disability, multiple stakeholders and levels are involved within the decision-making process and therefore a nuanced framework, able to capture the surrounding systems in detail, seemed an optimal solution. An ecological framework was deemed appropriate as it allows researchers to capture the complexity of processes (Onwuegbuzie, Collins, & Frels, 2013; Yin, 2002). Bronfenbrenner's (1979) theory of the ecology of human development requires the researcher to maintain a double vision: (i) identifying the dynamic relationship between the individual and his/her immediate environment and (ii) how this relationship is shaped by peripheral systems and forces.

TABLE 1 Search terms

Search terms population	Search terms context	Search terms context
Intellectual, learning, developmental, cognitive, neurodevelopmental, mental handicap, disability, difficulty, impairment, deficiency, incapacity, delay, disorder, retardation	Transition Adult services Adulthood Adult life Post-school Leaving school	Profound, complex, multiple, severe, dual, serious

TABLE 2 Overview of included studies

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound intellectual disability)
1. Biswas et al. (2016) UK	To explore parents' views of the transition of their child into adulthood	Recruitment was supported by various charitable organisations utilising non-probabilistic purposive sampling	12 parents of children with severe intellectual disabilities (age 44–78) 8 mothers, 4 fathers 11 young people (age 19–29, one child 57 ^a)	Interviews with parents using open-ended structured probing and non-directed probing Grounded theory used to analyse data	Identified an overarching theme of parents making comparisons with perceived norms of adulthood and the following themes: <i>Defining adulthood:</i> Using broad definitions of adulthood as starting point to understand transition. Differences in taking a chronological or developmental view <i>Noticing adult development:</i> Identifying biopsychosocial changes within own children. At times difficulty to identify signs of adulthood or to support gap between emotional, intellectual and physical development <i>Perceiving barriers to adulthood:</i> Necessity to rely on professionals. Continuing dependency of adult children <i>Worrying:</i> Transition as a "black hole." Concerns about safety, risks and long-term future <i>Making psychological adjustments:</i> Some parents encourage age-appropriateness while others continue to be accepting of children's 'child-like' interests Other parents are a source of support, while some participants find it difficult to share their experience
2. Carnaby et al. (2003) UK	To evaluate the involvement of students with learning disabilities within transitions meetings and to facilitate and evaluate subsequent practice improvements	Case study of one special school. Evaluation of practice (phase 1) and 4 year follow up of implementation of recommendations (phase 2)	Phase 1: 15 students and their families (age 16–18; mild-to-profound intellectual disability) Phase 2: 12 students and their families (age 16–18; mild-to-profound intellectual disability)	Qualitative data includes observations of meetings, field notes and reflection of themes present within decision-making process. No information on method used for qualitative data except stating that it included a review of main themes	The following themes were identified in relation to severe or profound intellectual disability: Little to no participation within transition meetings Lack of concrete future planning Last year of school "waiting" for transition to day centre Transport important for parents Use of creative methods such as video and photographs suitable to facilitate involvement of students unable to speak for themselves
3. Cox (2017) UK	To inform improvements by outlining themes and suggestions arising from experiences of transitions. The lived experience of young people and their families form the basis of the study	Participants from five different local authorities within Scotland. Recruitment through local organisations and services	29 families and additional consultation with professionals and service managers Young people (age 15–24) Disability: Ranging from "high functioning" to profound and multiple disabilities 10 cases were identified as meeting review definition of severe or profound in correspondence with author of study. Only data in relation to those 10 cases was included	Meetings and interviews with families and professionals. Semi-structured conversations. Use of questionnaires, charts, pictures and talking mats Gives summaries of all 29 case studies, followed by discussion of themes No mention of method employed to analyse data but uses "bridges" (strengths) and "cliffs" (weaknesses) to frame the narratives of cases and makes reference to "lived experience" as underlying approach	The following themes were identified in relation to severe or profound intellectual disability: Need for an understanding of the whole family system and a life course perspective Need for continuity within the co-ordination of transition Need for professional guidance and detailed information Need for partnership work across professional and family systems Need for support and respect for parents and carers

(Continues)

TABLE 2 (Continued)

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound intellectual disability)
4. Dee and Byers (2003) UK	To improve quality of life for people with profound and complex learning difficulties during periods of transitions To explore inclusive environments and to foster inter-agency collaboration and staff development	3 year project working across four case study sites and involving a variety of stakeholders in the dissemination of produced project material	4 case study sites One specialist college, one sector college, one community-based adult education and one social and employment services Dissemination phase: colleges, universities, schools, day centres, therapy services, students and families	<i>Action research phase:</i> Working with 4 case study sites to identify areas of improvement Interviews, field notes, observations and focus groups. Using data to produce project material <i>Dissemination phase:</i> Working with organisations and individuals to explore how to improve service provision No mention of method used for data analysis	The following themes were identified in relation to severe or profound intellectual disability: Often no transition procedures in place to support young people moving on Further adult education can make a contribution to the lives of adults with profound and complex learning difficulties There is a paucity of provision post-school, as well as wide regional variations Provision is fragile, relying on short-term funding and/or committed individuals. An understanding of individual's unique communication behaviours is important
5. DeZonia (2008) USA	To examine parent, teacher and institutional formulations of adulthood for students with profound developmental disabilities	Recruitment through special educational schools with the researcher being the director and founder of one of the schools. Utilisation of stratified non-random sampling	8 trio's of students, parents and teachers 8 teachers within public (2) and private (6) schools 8 parents (age 36–62) 7 mothers, 1 father, 6 white, 2 latino 8 students (age 16–21) Disability: Autism (5), Cerebral Palsy (2), Down syndrome (1)	Multiple case study and triangulation of multiple methods Interviews, educational documents (IEP, ITP) and governmental documents, field notes and online newspaper blog ^b Cross-case, constant comparison, inductive analysis	The following themes were identified in relation to severe or profound intellectual disability: Parents, teachers and institutional settings have differing perspectives on adulthood and future adult lives for people with profound developmental disabilities IEP and ITP goals are more consistent with teacher's views compared to parents and institutions There is a need for information on future options for teachers and parents
6. Doyle (2012) UK	To gain insight into the experiences of parents whose children are transitioning to adult services and to identify key themes relating to parents' experiences during the transition	Study conducted within an ethnically diverse outer London borough with participants from BME communities Parents recruited through one special school utilising purposive sampling	5 mothers of children with profound intellectual disabilities Ethnicity: Bangladeshi, Sri Lankan, African, Filipino, Caribbean/ British 5 young people (age 17–18) Disability: Cerebral Palsy (3), Autism (1), Leigh's Syndrome Mitochondrial Disorder (1)	Interpretative Phenomenological Analysis (IPA) utilising semi-structured interviews	The author identified the following themes: <i>Young Person's diagnosis:</i> Moment of diagnosis still very present in mothers' narratives. <i>Young peoples' needs</i> become more complex towards adulthood <i>Experience of transitions:</i> Anxiety about transition process and confusion about expected roles <i>Planning for the future:</i> Concerns about recent cuts and impact on transition. Worries about quality and suitability of adult provision. Difficulty to know what young people want themselves <i>Experience of working with professionals:</i> Positive and negative experiences of working with professionals. Parents would like smaller transition meetings and be guided more by professionals

(Continues)

TABLE 2 (Continued)

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound intellectual disability)
7. Dyke et al. (2013) Australia	To explore the perspective of mothers on the transition to adult life for their children with Down syndrome ^c compared to mothers of daughters with Rett-syndrome	Purposive sampling. Sample selected through two national databases Participants from both rural and urban areas	7 parents of 7 young adults with Down syndrome 11 mothers of young women with Rett-syndrome (age 19–33) Living arrangements of young women with Rett-syndrome: 6 with family, 4 supported accommodation and 1 partly home and partly in supported accommodation	Qualitative semi-structured phone interviews Transcripts were manually coded using content analysis	Authors identified the following themes: <i>Adult roles assumed during the day:</i> Transition process characterized by uncertainty with limited information. Need for strong parental advocacy No involvement of the young person in decision-making process <i>Accommodation:</i> Worries in relation to future living arrangements and wanting to outlive children. Difficulty to secure supported accommodation <i>Quality of life:</i> Most mothers describe own QoL as poor. Concerns about own ageing <i>Living a "good" life:</i> Most mothers believe daughters live a good life <i>Family impact:</i> Loss of safe environment of school and loss of other informal support networks and impact on maternal employment. Importance of transport
8. Gauthier-Boudreault, Couture, et al. (2017) Canada	To propose realistic solutions to meet the needs of adults with profound intellectual disability and their families during and after the transition to adulthood	Recruitment through intellectual disability rehabilitation centres utilising both convenience and snowball sampling	14 parents of young adults with profound intellectual disability ^d (age 18–26)	Descriptive, interpretative approach employing two semi-structured interviews First interview to document different solutions and second interview used to validate and deepen the researcher's understanding of themes	Authors identified the following themes: <i>Need for informal support:</i> Lack of information on procedures and responsibilities and lack of information sharing between stakeholders resulting in increased demands placed on parents Need to develop a step-by-step transition plan starting 3 years before end of school. Responsibility of coordination should be placed with a professional <i>Need for material support:</i> Lack of full-time day care services. Need to increase available places and to continue to support learning and development of skills <i>Need for cognitive support:</i> Lack of understanding of profound intellectual disability within services resulting in unsuitable approaches and lack of stimulation. Need for training for staff <i>Need for emotional support:</i> Lack of emotional support for parents during the transition process. Need to create parent support groups with professional input
9. Haddow (2004) UK	To investigate the experiences of family carers in relation to Future-Needs- Assessments, transition process and provision of post-school placements To explore practice improvements and to develop criteria for good quality provision and services	Four cases from one local authority in Scotland utilising purposive sampling	4 Families with children with profound and multiple learning disabilities (young people age 19–27) 5 Professionals: Education, Social Work, Health, third sector	Multiple case studies Interviews with data presented as 4 case stories. Interviews analysed using "interpretative-descriptive" method informed by grounded theory Uses interview data and analysis of documents to develop focus groups focusing on practice improvements Policy discourse analysis used to analyse documents Uses nominal group technique to develop quality criteria for adult provision	The author identified the following themes: <i>Information:</i> Lack of information about assessments and the transition process <i>The FNA process:</i> At times not all stakeholders present at meetings. At times there is a lack of knowledge about the young person's needs or available services. Little progress is made between meetings <i>The transition period:</i> Difficulty of arranging transition with post-school places being identified late or not at all <i>Post-school provision:</i> Lack of available provision. Provisions often not able to meet complex healthcare needs. Provision is short term and there is uncertainty about long-term future provision

(Continues)

TABLE 2 (Continued)

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound intellectual disability)
10. Hollinrake (2005) UK	To gain an understanding of how parents make sense of the transition time and to explore if there are differences within coping	Recruitment supported by one local authority social care services department utilising purposive sampling Study area rural and predominantly "white"	20 parents with children with severe intellectual disabilities. 15 mothers, 1 father, 4 parent pairs 18 Young people (age 18–29) Disability: cases with challenging behaviour (11), epilepsy (9), autism (5), health difficulties (4), physical disability (3), non-verbal (4), very limited communication (5), limited verbal abilities (9)	Phenomenological approach Semi-structured interviews and field notes Grounded theory used to analyse data	The following themes were identified in relation to severe or profound intellectual disability: <i>Overarching theme:</i> Being a main carer is demanding, enduring, time-consuming and intense Three different groups identified across participants in relation to their views, adaptation and coping styles. Groups are named (1) Balanced and resilient, (2) Self-reliant and rational and (3) Preoccupied and overwhelmed
11. Hubert (1991) UK	To understand the worlds of families caring for young people with severe learning difficulties To describe the lives of families with a focus on respite services and families who choose to keep their children at home	Participants from one county in southern England. Participants recruited through special schools, residential care services and social and health care professionals	20 families Young people (age 15–22) disability: Some described as immobile, some mobile with additional behaviour problems Study heavily based on involvement with mothers	Ethnographic research study. Researcher spend 2 years with families Several in-depth interviews, observations, participating in daily life activities and interviews with others such as professionals 5 families selected as in-depth case studies Study discusses a variety of themes. Data only included in relation to transition	The following themes were identified in relation to severe or profound intellectual disability: Transition from children respite service to adult services is traumatic and distressing for parents and young people. Too abrupt Young people's needs increase in adulthood while there is less respite provision. Provision is often uncoordinated, less reliable and haphazard Age-appropriateness seems more important within adult services than individual needs Parents would like smaller units with groups of young people with similar ages Parents worry about the future and being ageing carers
12. Murray (2006) Australia	To explore the experience of parents and their care work during transition to adult services	Study advertised in newsletter of a support and advocacy organisation. Other participants recruited through subsequent snowball sampling Participants from two different regions: Melbourne and regional Tasmania	8 mothers with daughters with severe or profound intellectual disabilities Young women (age 16–24) Disability: majority neurodevelopmental disorder. All with intellectual and physical disabilities	Qualitative semi-structured in-depth interviews Transcripts coded by key themes	The author identified the following themes: <i>Leaving school: Transition or continuation?</i> Leaving school connected to moving setting and not to an increase in independence or attainment of adult status Transition from paediatric to adult health care additional big change and less respite services available. Future worries in relation to dependency across lifespan <i>Finding a suitable programme:</i> Demanding and stressful time for parent. Difficulties in accessing right information <i>Families' involvement in developing new programmes:</i> Several mothers developed individualised programmes to meet their daughters' needs and challenge expectations to fit into existing services

(Continues)

TABLE 2 (Continued)

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound intellectual disability)
13. McIntyre, Kraemer, Blacher, and Simmerman (2004) USA	To describe and evaluate the quality of life (QoL) for adult children with severe intellectual disabilities from their mothers' perspectives in relation to their current life stage of transitioning into adulthood Focus of the study is more on quality of life rather than the transition process	Participants recruited through Southern California Regional Centres	Mothers (mean age 49.4) of 30 young adults with severe intellectual disability Young adults ^a (age 18–24) Disability: Cerebral Palsy (11), Down syndrome (1), Autism (4), intellectual disability only (14)	Dominantly qualitative methodology utilising two interviews and open questions alongside a standardised quality of life questionnaire Interviews recorded verbatim and coded	The following themes were identified in relation to severe or profound intellectual disability: A qualitative analysis using interviews was more meaningful to form an understanding of QoL for this population as reported by mothers in contrast to using the standardised QoL questionnaire during the first interview Mothers highlight the need to meet their children's basic needs, to offer activities that keep their children busy and to provide social interactions in providing a good quality of life Family is important for young people Communication difficulties, challenging behaviour and health concerns impact on young people's QoL Independent living skills are valued by mothers whose children have exited school. There is a tension between the hope for independence and young people's needs and abilities The QoL of the young adult is interdependent with parent's QoL
14. Young-Southward et al. (2017) UK	To explore transition experiences of young adults with intellectual disabilities and their parents. To identify health and well-being implications.	Recruitment through special education schools and organisations providing support to individuals with intellectual disability across the West of Scotland	26 young people (age 16–27) Disability: mild intellectual disability (7), moderate intellectual disability (4), severe (7), profound (8) ^b 23 carers, 20 mothers, 2 fathers, 1 grandfather and 1 grandmother 6 young people with severe intellectual disability present during interviews in the other cases of young people with severe or profound intellectual disability interviews only with carers	Hermeneutic qualitative design employing interviews alongside behavioural screening and general health questionnaire (SDQ and EQ-5D) Semi-structured interviews with young people, their carers or both Thematic analysis deploying emic and etic coding categories	The following themes were identified in relation to severe or profound intellectual disability: Increase in challenging behaviours for some young people on leaving structured school environment leading to exclusion from services and thus alleviating lack of routine and activities Parents struggle with the widening gap between their children's abilities and adult norms such as independence. Thus the transition is perceived to be primarily organisational instead of developmentally Parents envision caring for their children into old age but hope for the attainment of some independence such as a move to supported accommodation for their adult children in the future

^aData relating to this case was excluded due to age of child and indication that child did not meet criteria for severe or profound intellectual disability.

^bNot referring to transition and therefore excluded from review. Referring to case study of public opinion in relation to individuals with profound intellectual disability.

^cData relating to young people with Down syndrome was excluded due to indication that young people did not meet inclusion criteria of severe or profound intellectual disability.

^dBased on APA definition.

^eNot all young people in the study fit the definition of profound or severe intellectual disability with some described as having a paid job or being able to express their views to some extent.

^fBased on Vineland adaptive behaviour scale-II.

2.6 | Data synthesis

Qualitative data were extracted from all 14 identified studies. This included not only original data but also themes and meanings that were highlighted by authors. Abstracts, introductions, results and the discussion sections were included, as authors made references to their results throughout the included journal articles. Due to issues of feasibility, only results sections of the included government report, PhD theses and the one book were extracted. The ecological framework was systematically applied to the findings, and themes proposed by the authors were set aside. The framework codes and subcodes were applied to the findings using NVIVO qualitative analysis software (Version 11). Thus, the existing model acted as the base that was built upon, changed, reduced and combined within the process. Throughout the process, the development of the framework was documented and changes were applied to all studies continually. Towards the end of the analytic process, a second researcher used the framework and applied it to a selected sample of the data. The final application of the framework was discussed within the research team.

3 | RESULTS

Overall, studies reflected the variety of needs and heterogeneity of abilities in young people with severe or profound intellectual disability. The samples ranged from individuals with complex healthcare needs and limited mobility, to young people who were physically very able but who required constant support and supervision within daily life. The latter group was often described as being on the autistic spectrum. Sample sizes ranged from four to 26 participants. The majority of studies utilised interviews to explore the transition process through the perspective of parents. A minority of studies explored the perspectives of different stakeholders and therefore were able to address the ecological framework. These included a focus on transition meetings (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003), further education and inter-agency work (Dee & Byers, 2003); three studies (Cox, 2017; DeZonia, 2008; Haddow, 2004) related the perspectives of parents to views of professionals and organisational practices and policies. Additionally, one study explored the views of parents within Black and minority ethnic (BME) communities (Doyle, 2012): a gap within the literature of intellectual disabilities and across the included studies.

Studies that included participants with mild-to-profound intellectual disability (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; McIntyre et al, 2004; Young-Southward et al, 2017) provided less relevant data than those with an exclusive emphasis on severe or profound intellectual disability.

In most studies, young people themselves were not involved in the research process and choices made about the involvement or exclusion of young people as participants were not discussed by the majority of studies. Interestingly, the lack of involvement of young people in the transition process appears to be mirrored in their lack

of involvement in the research process. Yet, three studies were able to give presence to young people's lives and identity within the narratives of their studies. This was achieved by in-depth case studies and descriptions of the likes and dislikes of young people. One study described the use of art, pictures or Talking Mats™ (Murphy & Cameron, 2006) to involve young people directly in the research process (Cox, 2017), while Hubert (1991) and Haddow (2004) described spending time with young people and family members during the research process. Young-Southward, Philo, and Cooper (2017) reported that some young adults with severe intellectual disability were present during interviews alongside their parents, but visual aids were not provided due to experiences resulting from a pilot study. Young people who were present during interviews appeared to be able to express their views verbally about the transition, and hence not meeting inclusion criteria for this study. Young people with profound intellectual disability were not present during interviews.

3.1 | Themes across ecological levels

Bronfenbrenner's ecological framework was considered suitable to synthesise findings. Notably, two changes required to be made to the framework during the analytic process. Firstly, it appeared more appropriate to have the family, as opposed to the young person, at the centre of the framework. This might be explained partly by the designs of the included studies, as all relied predominantly on descriptions of the young people as seen by parents. With regard to planning for adulthood, the needs, wishes, concerns and views of parents were discussed concurrently with the perceived needs and possible wishes of young people. Often, when reviewing, it was challenging to understand whether addressed wishes and needs related to young people or to their parents. Therefore, the decision was made to take the whole family as the first system.

Secondly, at the beginning of the review, the chronosystem had been thought to be useful to capture the transition as a process over time. However, within the analysis, it became apparent that time was a more important theme, spanning the whole life course of young people and their families from the time of birth and diagnosis to the far future when parents might cease to be able to care for their adult children. An incorporation of the theme of time facilitated an understanding of the transition within the whole life course of the young person and his/her family. Thus, it was decided that the immediate decision-making process of ending school and starting adult services was better captured within immediate family systems (Micro and Meso). An overview of the a-priori and a-posteriori framework can be seen below (Tables 4 and 5). Subthemes comprised environments and processes that were identified as influences within different ecological levels.

Some themes were discussed in more detail than others. As can be seen in Table 6, themes relating to the first three systems were discussed by more studies than, for example, cultural or political influences. Themes relating to the family system showed the

TABLE 3 CASP assessment

Study	Aims and purpose	Suitability of qualitative design	Link between aim and study design	Participant selection	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Strengths and weaknesses
Biswas et al. (2016)	++	++	+	++	++	++	++	++	++	++	Detailed account of analytic process and ethical considerations. Coherence within all aspects of study No discussion on why grounded theory was chosen. One adult child a lot older than others recruited. No discussion of impact of choosing an age range from 19 to 57
Carnaby et al. (2003)	+	++	+	+	++	0	0	+	+	++	Involvement of different stakeholders No mention of ethics and little information on the research process and the process of qualitative data analysis No information on overall number of participants meeting severe/profound definition. From eight meetings recorded only one meeting with student meeting inclusion criteria
Cox (2017)	++	++	+	++	+	+	++	+	++	++	Inclusion of young people with severe or profound intellectual disability within study through visual methods and spending time Little information on data collection and analysis
Dee and Byers (2003)	++	+	+	+	+	0	0	0	+	++	Involvement of different stakeholders Lack of detail in relation to data collection and analysis. No mention of ethical considerations and no example data presented Article limited to do justice to scope of project Other articles connected to project have quantitative focus and were consequently excluded
DeZonia (2008)	++	+	++	++	++	++	0	++	++	++	Involvement of different stakeholders. Reflective of researchers' own role No mention of ethics Poor discussion on using quantitative analysis alongside dominantly qualitative design while comparing parent/teacher thinking and IEP and ITP goals

(Continues)

TABLE 3 (Continued)

Study	Aims and purpose	Suitability of qualitative design	Link between aim and study design	Participant selection	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Strengths and weaknesses
Doyle (2012)	++	++	++	+	++	++	++	++	++	++	Focus on BME communities. Strong coherence within all aspects of study Four participants had English as an additional language. Interviews were conducted without a translator present. Difficulties in conducting and transcribing the interviews were noted by the researcher
Dyke et al. (2013)	+	++	+	++	++	+	+	++	++	++	Aims not clearly stated and no discussion on link between research aim and method chosen
Gauthier-Boudreault, Couture, and Gallagher (2017), Gauthier-Boudreault, Beaudoin, et al. (2017), Gauthier-Boudreault, Gallagher, et al. (2017)	++	++	++	++	+	+	++	++	++	++	Very comprehensible and coherent study throughout One participant was unreachable for second interview
Haddow (2004)	++	++	++	+	++	++	+	++	+	++	Involvement of different stakeholders. Researcher reflexive of own role as a mother of a young woman with profound intellectual disability Little information on the recruitment process and no mention of ethical approval
Hollinrake (2005)	++	++	++	++	++	++	++	++	++	++	Reflexive account of the research process given with an in-depth discussion of ethics Coherent study throughout

(Continues)

TABLE 3 (Continued)

Study	Aims and purpose	Suitability of qualitative design	Link between aim and study design	Participant selection	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Strengths and weaknesses
Hubert (1991)	+	++	++	+	+	++	0	+	++	+	In-depth reflection of author's own involvement as researcher. Research involvement over 2 years There is a lack of information on recruitment, data collection and analysis and little use of existing literature. No mention of ethical considerations
Murray (2006)	+	++	++	+	++	+	+	+	+	++	No clear statement of research objectives. Little information on analysis
McIntyre et al. (2004)	++	+	+	++	++	0	0	+	++	++	Discusses the issue of proxy reporting No mention of ethics. Little information on data analysis As not all participants and themes met the inclusion criteria only a small amount of data was included for the review
Young-Southward et al. (2017)	++	++	+	++	++	0	+	++	++	++	High credibility of findings with high degree of consistency found in identified themes Use of quantitative questionnaires alongside qualitative interview not discussed Only small amount of data relevant for review

TABLE 4 A-priori framework

Master theme
The Individual
Microsystems
Mesosystem
Exosystem
Macrosystem
Chronosystem

TABLE 5 A-posteriori framework

Master theme	Subthemes
The Family	The young adult Parents Quality of life
Microsystems (Changing networks)	Ending school Perceptions of adult services Additional networks
Mesosystem (Decision-making and Collaborative Practice)	Choice and information Roles and relationships Involvement of the young person
Exosystem (Organisational Context)	Coordination of services Budget and funding processes
Macrosystem (Society)	Culture Politics and economy
Chronosystem (A Life-course perspective)	From past to future

greatest complexity and content provided. Other themes such as the organisational context were widely mentioned, but the degree of elaboration was less. Participants appeared to acknowledge the role and importance of “wider” ecological systems, while not being deeply involved in them and having little information about how they worked.

THE FAMILY

The subthemes within this master theme mirror the interdependence of the young person's needs and needs of the family as a whole. These two subthemes describe young adults and parents separately, while the third theme “Quality of life,” explores issues discussed in both.

The young adult

Difficulties with communication, and the question of how to involve young people and access their views, were highlighted as problematic by participants across all studies. However, the need to understand and engage with individuals was emphasised in eight studies (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Cox,

2017; Dee & Byers, 2003; DeZonia, 2008; Gauthier-Boudreault, Couture et al., 2017; Haddow, 2004; Hollinrake, 2005; Hubert, 1991). These studies highlighted the importance of attuned and consistent relationships, valuing the unique and subtle communication of individuals.

Adolescence and the move into adulthood had the potential to result in an increase of support needs, in relation to health needs, mental health or behaviour that challenges. For example, while young people physically matured they became larger and stronger and care tasks as well as behaviour that challenges were more difficult to handle for carers. The gap between young people's intellectual development and their emerging sexuality was described as a concern within three studies (Biswas et al., 2016; Cox, 2017; Hollinrake, 2005).

There was some fluctuation in both parents' and professionals' accounts that described small developmental steps towards adulthood and more independence, while also acknowledging the consistency of needs of young people and seeing them as “eternal children” (DeZonia, 2008).

There's something that's still inside saying he's my little boy. It's a bit peculiar and you don't have the normal signals to tell you this child has grown up. (Hollinrake, 2005)

In relation to developmental processes that were observed by participants, this related to greater abilities in choice making and life skills, comprising small steps for example learning to carry a laundry basket (Biswas et al., 2016).

Parents

In the majority of studies, parents were acting as main carers. Parents' responsibilities involved daily care tasks such as personal care, medical care, facilitating meaningful activities and advocating on behalf of the young people. Parents also managed collaborative practice with involved professionals such as social workers, teachers, health professionals and third sector agencies or respite services. Mothers accounted for the clear majority of participants in the study sample.

Consistent, or increasing care demands, within young adulthood, were at once described in the context of parents becoming older and being less able to meet all the needs of young people. In five studies, parents described how the birth of their children had taught participants a new perspective on life and the deep love inherited within the relationship (Cox, 2017; DeZonia, 2008; Haddow, 2004; Hollinrake, 2005; Hubert, 1991).

I love her very much and she's taught me a lot of lessons in life. I think about how everything is a struggle for her, you know? (...) It has taught me how not to give up in life and my own challenges in life. I look at her and think everything is a struggle, and when I have a rough day I think about Linda and it helps me move on. (DeZonia, 2008)

Quality of life

Quality of life (QoL) of the young people was framed around meeting basic healthcare needs, providing activities and space for social interaction and stimulation. The responsibility to provide adequate QoL appeared to heavily rest on the family, especially mothers. Concerns about the QoL of parents dominated the analysis and were discussed by all studies except the two studies whose focus was not on parents (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Dee & Byers, 2003). Offering a high QoL for their children seemed to negatively affect parents' own QoL. Parents were struggling with a lack of sleep and little time for themselves. Siblings were only mentioned in four of the studies (Cox, 2017; DeZonia, 2008; Haddow, 2008; Hollinrake, 2005), and parents seemed to try to discourage siblings to feel responsible to take on caring roles.

Moving out of the family home was discussed in eight (Cox, 2017; DeZonia, 2008; Doyle, 2012; Dyke et al, 2013; Haddow, 2004; Hubert, 1991; Murray, 2007; Young-Southward et al, 2017) of the studies and in six studies (Biswas et al, 2016; Cox, 2017; Dyke et al, 2013; Hubert, 1991; McIntyre et al, 2004; Young-Southward et al, 2017) some young people lived in supported accommodation or residential placements, but this was the minority of cases with most young people living in the family home. There were variations in families who wished their adult children to move out of the family home, advocating for their children's right to independence, while, at times simultaneously, parents had little trust in services to be able to adequately care for their children. Two studies described that some parents felt their own QoL had increased once their children were looked after outwith the family (Dyke et al, 2013; Hubert, 1991), while other participants reflected on their perceptions of poor quality of care within residential or supported living services (DeZonia, 2008; Doyle, 2012; Hubert, 1991).

A wish for more support outwith the family lived alongside parental worries of risk and safety. Those fears seemed to stem from media coverage, but also direct experience of adult services.

There are horror stories about care homes and things, with abuse, and the worry was if she goes away and she's abused, how would she be able to tell us? Because if she went very quiet, that wouldn't be her, but then the carers don't know her. So they wouldn't pick up on it either.
(Biswas, Tickle, Golijani-Moghaddam, & Almack, 2016)

The thought that parents would have to continue to provide substantial care until the end of their lives was described as a very difficult process by some participants.

It's a daunting feeling because ... the older they get the more reality hits that you're like 'I'm going to be a carer for the rest of my life'. (Young-Southward et al., 2017)

There were too little data to make any judgement on types of accommodation in relation to quality of services, but the need for

trusting relationships with qualified staff was emphasized by parents in eight studies (Biswas et al, 2016; Cox, 2017; DeZonia, 2008; Gauthier-Boudreault, Couture et al, 2017; Haddow, 2008; Hollinrake, 2005; Hubert, 1991; Murray, 2007).

CHANGING NETWORKS

The subthemes included "Ending school" and "Perceptions of adult services" and captured the process of moving from school to adult services. "Additional networks" described systems that had an influence on participants' experiences of transitions. There was a significant overlap with the previous theme "Quality of life," which discussed the impact of leaving education and starting adult services on the QoL of both parents and young people.

Ending school

Ending school related to a feeling of loss. This was described in relation to the loss of a focus on learning and therapy services, and the loss of a well-known environment. As previously stated, uncertainties about young people's future lives increased anxiety, worries and stress for families.

I was really scared ... it was a really emotional time and because you are leaving this environment that you've been a part of for 15 years. (Dyke, Bourke, Llewellyn, & Leonard, 2013)

Perceptions of adult services

Participants described a change in approach in adult services, and there appeared to be a conflict between adult norms, which may be encouraged within adult services, and their children's developmental age.

Studies described that within adult services, young people either accessed home-based services, outreach services, day centres or a mix of the above. Parents expressed worries about adult provision compared to the school environment in relation to programs, peer-networks, equipment and hours offered.

We didn't want someone to take Geri out in the car to take her round the shops and sit in coffee malls all day.
(Haddow, 2004)

For young people with challenging behaviour (Cox, 2017; DeZonia, 2008; Doyle, 2012; Hollinrake, 2005; Hubert, 1991; McIntyre et al, 2004; Young-Southward et al, 2017) or complex medical needs (Cox, 2017; Haddow, 2004; Hubert, 1991) there appeared to be fewer services able to meet their needs.

Parents described an ideal adult placement as centre-based with small, same-aged groups, which facilitated learning and skills, and that was available 4–5 days per week, staffed with caring and

qualified staff. Transport stood out as a topic (Cox, 2017; Dyke et al, 2013; Haddow, 2004; Hollinrake, 2005; Murray, 2007) and there seemed to be issues to secure transport funding, while parents described transport as highly important for them to be able to continue to work and offer them respite.

Additional networks

The move to adult day or supported living services was accompanied by other transitions, such as the move from child to adult respite services (Cox, 2017; Haddow, 2004; Hollinrake, 2005; Hubert, 1991; Murray, 2007). This was reported to be a significant difficulty, as the amount of hours decreased in adult respite services compared to child respite, resulting in young people being at home more. Parents struggled with the reduction in respite, as the needs of young people remained stable and at times increased. Two UK studies described respite transitions happening at the age of 16 and before the end of school (Cox, 2017; Hubert, 1991).

How will families barely coping in school years cope with reduced services in adult years? (Cox, 2017)

Additionally, the transition to adult healthcare services was emphasized as an additional and worrying change. The transition to adult health care was discussed in detail by three studies (Cox, 2017; Haddow, 2004; Murray, 2007) and related dominantly to young people with complex healthcare needs such as epilepsy.

Other parents were seen as a welcome support system for families, especially in relation to sharing information on processes, existing services and the offer of emotional support. Yet, a few families spoke about feeling socially isolated and feeling that the behaviours of their children were not understood or accepted within their communities (Biswas et al, 2016; DeZonia, 2008; Doyle, 2012; Dyke et al, 2013; Haddow, 2004).

It's not well understood out in my community you know when they see him behave bad they don't always accept he's disabled. (Doyle, 2012)

DECISION MAKING AND COLLABORATIVE PRACTICE

The Mesosystem comprised three themes in relation to decision making and collaborative practice.

Choice and information

Across all studies, a lack of options and choices was described; this was one of the strongest themes in relation to the amount of content that was provided by all studies. Parents and, in a few instances, also professionals, such as education (DeZonia, 2008) and social

work professionals (Cox, 2017; Murray, 2007), felt that there was a lack of guidance and information about the transition process. Many parents suggested that a list of available local services would be instrumental in supporting them to understand options and choices.

Give us a directory of resources and processes. We have no time to run around doing research (Cox, 2017)

Lack of choice was linked to parents accepting "inadequate" offers as they felt they needed to work with what was available.

I have got to make a compromise if you like that it is not what I would really want but until I can get what I really want we have just got to accept that this is the only thing that is there for her. (Murray, 2007)

Roles and relationships

There was variability across studies describing the quality of collaborative practice. Tension between parents and professionals was identified as a barrier to successful transitions, while some parents spoke of individual professionals as their main support system. Tensions seemed to be related to the discrepancy between parents' perception of the extensiveness of needs of the young person, in contrast to services and resources available to them. A difference in perspective between parents and teachers was highlighted by DeZonia (2008) in relation to priorities in future planning.

Meetings appeared to be arranged through schools, while budget and funding decisions lay with Social Work. Funding decisions appeared to be especially powerful in shaping the transition process. For example, even when parents started the planning process early, uncertainties remained if budget decisions were not made and last minute budget decisions could result in periods without support for families. In most cases, parents were strong advocates for their children, visiting available services and acting on behalf of their children. However, three studies (Carnaby et al, 2003; Doyle, 2012; Hollinrake, 2005) were able to show a different perspectives from some families where parents felt uncomfortable acting in an advocacy role and taking the lead in working with professionals.

I still don't know Mark's behaviour, what Mark needs and don't need you know... It's so hard to know – his behaviour is different in different places depends on who he's with. I'd rather school take over – sort it for me. I don't know answers really (...) (Doyle, 2012)

Involvement of the young person

Another strong theme was the lack of involvement of the young person within the transition process. Due to communication difficulties, young people were largely excluded and parents acted on the behalf

of young people. Parents based their decisions on the known preferences of their children. Only in Doyle's (2012) study did parents voice concern about their role.

The difficulty of facilitating participation of the young person was discussed across all studies, with four studies discussing possible means to facilitate participation; for example, through the use of videos and photographs (Carnaby et al, 2003; Dee & Byers, 2003) or professionals spending time with young people (Carnaby et al, 2003; Gauthier-Boudreault, Couture et al, 2017; Haddow, 2004).

I think it helped the [intellectual disability rehabilitation centre] that did not know her apart from a picture, but then they really saw her interaction, they really saw her strengths and limitations. (Gauthier-Boudreault, Couture, et al., 2017)

ORGANISATIONAL CONTEXT

Subthemes related to coordination of services and budget and funding processes.

Coordination of services

As many different professionals were involved in the decision-making process, participants asked for more transparency and clearer pathways to responsibility and accountability (Cox, 2017; Dyke et al, 2013; Gauthier-Boudreault, Couture et al, 2017; Haddow, 2004; Hollinrake, 1995).

Parents spoke about the need for continuous support throughout their children's lives and there seemed to be a need for services that were able to accompany them and plan for future changes.

We don't know what would happen or where she would go ... we've got an aged care facility and I look at that and think that could be our option which is a scary option. (Dyke et al., 2013)

Budget and funding processes

Families struggled to understand how budget decisions were made and this seemed to increase tensions between families and local authorities.

An increase in individualised and self-directed support appeared to have potential to allow parents to create a care package they found most suitable, able to facilitate support that was more flexible and person-centred. At the same time, the management of organising individualised packages was described by some parents as demanding and stressful and some current packages appeared to not be able to cover what families would ideally like.

Complexity of managing personal care team under SDS – 'needs the skills of running a small business.' (Cox, 2017)

SOCIETY

This theme encompassed data that related to cultural norms and values and the current political climate. Both themes were only tentatively sketched and especially within the realm of politics and economy, there were only a few excerpts of data across studies that described participants' views on this theme.

Culture

Societal norms of adulthood were seen in conflict with abilities and opportunities in the lives of individuals with profound and severe intellectual disabilities. References to a "meaningful" adult life were made but it often remained unclear what such a life could look like. Especially parents, and to a lesser extent professionals (Cox, 2017; DeZonia, 2008; Haddow, 2004) seemed to feel a tension between recognising that young people had different needs and were following different life paths, while at the same time, hoping for or working towards the attainment of some "normality." This "normality" for young people was viewed as having peer groups of a similar age or living out with the family at some point in the future.

Oh, I wish....and you're breaking down crying because you think what the hell do you buy him... if he'd been alright you'd be buying him his car now, you know, and all you can think of is a rattle or something. (Hollinrake, 2005)

Thus, this theme expressed a discrepancy between "typical" development and the continuing dependency on the family of young people with severe or profound intellectual disability.

The social worker kept saying to us all the time, 'of course you're not responsible for him anymore', I sort of joked with her when she said 'you're not responsible' and I said 'oh good, does that mean I can, I can nip off to the cinema then and just leave him here?' and she says 'oh no of course not'. (Biswas et al., 2016)

Two studies (DeZonia, 2008; Doyle, 2012) described how religion and faith offered support to parents and this was highlighted particularly within Doyle's study that focused on BME communities.

Politics and economy

There appeared to be ambiguity between policies and practice. Policies were described as promoting values such as autonomy and self-determination while young people were going to need high

TABLE 6 Framework applied to studies

The family			Changing network			Decision making and collaborative practice			Organisational context			Society		Life course perspective
Young person	Parents	QoL	Ending school	Adult services	Additional networks	Choice and information	Roles and relationships	Involvement of young person	Coordination of services	Funding processes	Culture	Politics and economy	From past to future	
1. Biswas	x	x		x	x	x	x	x	x		x		x	
2. Carnaby	x		x			x	x	x	x					
3. Cox	x	x	x	x	x	x	x	x	x	x			x	
4. Dee & Byers	x			x		x		x	x		x		x	
5. DeZonia	x	x	x	x	x	x	x	x		x	x	x	x	
6. Doyle	x	x	x	x	x	x	x	x	x	x	x	x	x	
7. Dyke	x	x	x	x	x	x	x	x	x	x			x	
8. Gauthier-Boudreault	x	x	x	x	x	x	x	x	x	x			x	
9. Haddow	x	x	x	x	x	x	x	x	x	x	x	x	x	
10. Hollinrake	x	x	x	x	x	x	x		x	x	x		x	
11. Hubert	x	x		x	x	x	x		x		x	x	x	
12. Murray	x	x	x	x	x	x	x	x	x	x	x		x	
13. McIntyre	x	x		x		x						x		
14. Young-Southward	x	x		x	x								x	

levels of support for the rest of their lives. Those who supported young people seemed to find it difficult to relate to these values or to apply them to their situation. Families felt that they were not seen as a priority by governments and left alone with the responsibility of care. Within a difficult economic climate available support and services seemed to decrease.

Do they think about kids who can't do anything – are they just left?
(Doyle, 2012)

A LIFE COURSE PERSPECTIVE: FROM PAST TO FUTURE

Participants spoke of transition as an ongoing process and anticipated further transitions due to the changing needs of the individual and family, ongoing reviews of care provision or services ending their support for young people by their mid-twenties. There was a clear need to understand the continuing dependency of individuals into the far future. At the same time, development was also present within some studies and young people were described as learning and changing.

Concerns about the long-term future dominated the narratives of parents and were discussed within nine of the included studies. The experience of diagnosis and early childhood on one side (DeZonia, 2008; Doyle, 2012; Haddow, 2004; Hollinrake, 2005; Hubert, 1991), and thinking about the long-term future and their own ageing at the other side (Biswas et al, 2016; Cox, 2017; DeZonia, 2008; Doyle, 2012; Dyke et al, 2013; Gauthier-Boudreault, Contour et al, 2017; Haddow, 2004; Hollinrake, 2005; Hubert, 1991; Murray, 2007; Young-Southward et al, 2017) framed the stories of parents. The biggest worry of parents related to what would happen to their children once they were unable to continue to be strong advocates.

3.2 | Relationships between themes

During the analytic process, the researcher became interested in the relationship between themes across the ecological levels. Thus, the data were also explored with a focus on influences of one level to another. As a starting point, the first researcher looked at the overlap of themes, examining extracts of data that were coded to more than one ecological level using NVivo (Version 11). Then, she went back and looked at the data line by line to look for descriptions of relationships.

An overarching theme of discrepancy emerged in relation to the experience of the family and the needs of the young person and wider ecological levels. Policies and societal values emphasizing independence and self-determination seemed to stand in contrast to lifelong high dependency. Additionally, a discrepancy seemed to exist between an organisational context that conceptualises the transition as an event, while parents asked for an understanding

that acknowledges their lifelong and continuing needs. However, relationships between systems were only tentatively sketched and studies did not provide detailed information on how different systems interrelate. Nonetheless, this does highlight an important issue of the extent to which high-levels policies in this area influence the outcomes for young people with severe or profound intellectual disabilities.

4 | DISCUSSION

This review has highlighted the needs and life paths of young people with severe or profound intellectual disabilities and their families. The transition from childhood to adulthood is often an exciting time in the lives of typically developing young adults. It is characterized by growing independence, leaving school and entering the world of employment or further education. It is a time when young people explore their identities, and relationships with others, outside the family, become more important (Arnett, 2015; Wehmeyer & Webb, 2012). This is a stark contrast to the experience of the transition to adulthood for young people and their families in the studies included in this review. The experience of “difference” has been highlighted by others (Nind, 2013; Simmons & Watson, 2014; Ward et al., 2003) and can lead to ambiguity for those supporting adults with severe or profound intellectual disability (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Dunn, Clare, Holland, & Gunn, 2007; Hubert, 2011). Jacobs and MacMahon (2017) found that the views of siblings illustrated this tension between difference and normality, of being both a different family, and being just like any other. It seems as if the experience of “difference” is more prominent in this context compared to the literature on those with mild or moderate intellectual disability, pointing to the need for research to differentiate within the spectrum of intellectual disability (Foley et al., 2012; Gauthier-Boudreault, Beaudoin, et al., 2017).

During the analytic process, the decision was made to have the family in the centre of the framework, as opposed to the young person. It might be argued that this is problematic and stands in contrast to “person-centeredness” and individualised approaches. However, within the field of severe and profound intellectual disability, it seems more meaningful to take a relational perspective (Grove, 2012; Simmons & Watson, 2014). Research shows that individuals with profound intellectual disability have little influence over their environments, with the family and school often remaining individuals’ main social networks (Kamstra, van der Putten, Post, & Vlaskamp, 2015; Wilder, 2008), coupled with a decrease in networks outwith the family towards adulthood (Gauthier-Boudreault, Beaudoin, et al., 2017).

Organisational and societal influences were described by the majority of included studies, but remained on the periphery of parental experiences or views. Those studies that incorporated different perspectives were able to illustrate organisational barriers and facilitators in more detail. For example, Cox’s (2017)

report described organisational barriers that correspond to a similar study by Hardy et al. (2005). In their comparative study on transitions for young people with intellectual disability and older people who suffered stroke, Hardy et al. (2005) found that interorganisational complexity, overlapping responsibilities and historic underfunding of adult social care acted as barriers to successful transitions. Hardy et al. (2005) found that the availability of resources and available options seemed to be particularly influential in relation to those with profound intellectual disabilities and that transitions were viewed as points in time rather than a continuous process. Although not specifically referring to young people with severe or profound intellectual disabilities, guidelines around healthcare transitions make a differentiation between transfer and transition. The transition is defined as the whole process involving early planning and later support while transfer refers to the actual move (Care Quality Commission, 2014; NICE, 2016). Understanding that transition is not a single process might be a good starting point. Parents seem to ask for an understanding of their children's lifelong need for support, defining transitions as complex processes that are inevitably interlinked with past and future.

How to involve young people in meaningful ways emerged as a problem across studies in relation to the transition process and the research process. Spending time with young people and the use of pictures and video seemed to be possible solutions. Similarly, a recent transition project (Art in Transition, 2008) made film portraits of young people accompanying them in their different environments and speaking with professionals and family members. The project describes how the use of multiple perspectives helped family members and professionals to see new facets of the young person. Thus, the incorporation of many perspectives might be able to aid a better understanding of young people with severe or profound intellectual disability in future research.

5 | LIMITATIONS

Although the review was able to identify themes across ecological levels, this was mainly from the perspectives of parents. Different stakeholders might highlight different themes and could add more clarity, or give more evidence of the complexity inherent in this area. Additionally, most studies stated that recruited parents were very proactive and engaged and thus views of parents might not be representative.

Transitions are processes that can span many months and years, but in most studies, researchers only collected data at one point in time. An experimental design able to capture changes and developments across time appears to be more suitable to describe the transition process as participants at the beginning of the process might have different views at the end of it.

All studies were published in English and conducted in countries of the western world. Comparisons to other cultural contexts could be considered in future studies.

6 | CONCLUSION

This review found that pathways and needs for young people with severe or profound intellectual disability differ. Thus, it can be argued that there is value in differentiating between degrees of intellectual disability and there seems to be a need to have more studies that focus on those with severe or profound intellectual disability.

Participation and user involvement are placed at the centre of present UK, EU and UN policies (DoH, 2001; EU, 2010; Scottish Government, 2013; UN, 2006). However, research suggests that when it comes to decision making, participatory practices are often limited to the individual level (Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Urek, 2017). Families and service users seem to have very little involvement in "wider" decision making such as service commissioning. Similarly, this review identified a lack of understanding of organisational and political decision making by families. Urek (2017) argues that to achieve true participation all ecological levels need to be given equal importance to avoid a widening of the gap between practice and the ideology of policies. In this review, relationships between the different ecological systems were only tentatively sketched. Yet, this seems to be an important avenue for future research. The influence of wider systems does seem to have an impact on the transition experience, while the question of how these influences operate in practice seems to be less well understood.

6.1 | Implications for practice and future research

The family appears to be the main support system for young people, highlighting the need for more substantial support for families in advocating and caring for their children.

Furthermore, the ecological synthesis highlighted the need for families to be involved across levels of decision making and to have more access to information and involvement in service delivery.

While reviewing full-text records of identified studies, it became apparent that authors gave different meanings to the terms severe or profound intellectual disability. Often, studies described participants with the ability to express their views, to live independently or be employed while using the terms severe or profound. Future research should show a greater awareness in using terminology and labels such as "sever," "complex" or "profound" and report levels of intellectual disability more clearly. Moreover, in cases of mixed samples, a discussion of differences within results sections is highly recommended in light of the above finding.

The exclusion of young people with severe or profound intellectual disability from the research process requires attention. The reasons for this may include ethical concerns in regard to consent and vulnerability, alongside the sheer complexity of involving individuals with profound communication difficulties in meaningful ways (Nind, 2013; Ware, 2004). However, a new body of research and the literature is exploring the possibilities of including individuals with profound intellectual disability within research (McVilly & Dalton, 2006; Nind, 2013; Simmons & Watson, 2014) and this should be considered by future studies. Additionally, in decision-making

processes, a variety of stakeholders are involved. Yet, research on transition for young people with intellectual disability seems to be largely limited to the views and perspectives of parents. An inclusion of multiple perspectives could aid a better understanding of how decisions are made between members who have the complex task of identifying what is in the best interest of another person.

Interestingly, studies highlighted similar concerns and barriers although the points in time of data collection spanned from the end of the 1980s to early 2017. Moreover, included studies encompassed five different countries and hence it is likely that the economic and political context varied between studies. Yet, similarities were more striking than differences within participants' accounts. Atkinson, Nind, Rolph, and Welshman (2005) argue for the need of a better understanding of the influence of social change on the lives of individuals with intellectual disability, stating that there appears to be a "continuing centrality" of the family in the history of intellectual disability (Atkinson et al., 2005; Johnson & Traustadottir, 2005). This might be an interesting starting point for future research.

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Who decides? – transitions from school to adult services for and with young people with severe intellectual disabilities

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ABSTRACT

The transition from school to adult services for young people with severe intellectual disabilities has been identified as an area of concern, particularly with regards to how young people can be involved in meaningful ways. Additionally, although available resources and organisational practices seem to play important roles, there seems to be a lack of understanding as to how societal influences shape the process. Our study presents case studies of three young people and their journey from school to adult services from an ecological perspective, examining the decision-making process in the context of multi-agency involvement. We suggest that each transition journey challenged conceptualisations about the involvement of young people in the decision-making process. While the practical aspects of the transitions were described as positive, barriers and limitations were identified in the wider organisational context. The only people who clearly talked about the transition in terms of the long-term future were the parents.

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Transition; severe intellectual disability; ecological framework; case study

Points of interest

- School often provides a support network and place of belonging for young people and their families. Once school ends, young people and their families make the transition to adult services and new care packages need to be confirmed.
- This study showed that available resources, policies and cultural beliefs influence decisions that are made.
- Both the funding available and lack of places in adult services greatly influenced the choices that were available to families.

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- Once it was decided where young people would go to, young people seemed to be more involved. For example, professionals and families made decisions about activities young people could do in their new service based on knowing about their preferences and likes.
- Speaking with everyone involved reflected the complexity of understanding what adulthood means for young people who will continue to need support throughout the course of their lives.

1. Introduction

The transition from school to adult services has been described as the “black hole” (Doran 2011) in the lives of individuals with intellectual disability and research has highlighted the need to improve practices in the UK (Stalker and Moscardini 2012; Cox 2017; Hudson 2006). This study builds on a systematic review concerning this transition for young people with severe intellectual disability (Jacobs, MacMahon, and Quayle 2018). The pathway to adulthood often differs for these young people (DeZonia 2008; Simmons and Watson 2014) and emerging adulthood can highlight the tension inherent in the gap between the individuals’ abilities, possibilities and the acquisition of adult status (Jacobs and MacMahon 2017; Pilnick et al. 2010, 2011; Biswas et al. 2017).

Within the transition to adult services, research shows that external factors have a significant influence on decision-making. Decisions are made by statutory services and families, and policies and resources available in local areas play crucial roles (Jacobs, MacMahon, and Quayle 2018; Hardy et al. 2005; Lenehan 2017). An ecological understanding to transitions has been shown promising in mapping facilitators and barriers across systems (Small, Raghavan, and Pawson 2013). Bronfenbrenner’s (1979) ecological framework captures how change happens in an interdependent and relational manner. Jacobs, MacMahon, and Quayle (2018) utilised an ecological perspective to data synthesis in their systematic review but the influences of wider systems were only tentatively sketched. It was hoped that using the ecological framework for both data collection and analysis in this study would achieve a deeper understanding of intersections between culture, policy, economy, organizational practices, local resources and the lived experience of those affected, particularly at current times of austerity (Hardy et al. 2005; Mansell 2010; Power and Bartlett 2018; Stalker and Moscardini 2012). Promoting participation of those at the core across ecological levels, not solely in relation to their immediate environment, has started to gain importance within policy development (Omeni et al. 2014; Urek 2017). The UN Convention on the Rights of Persons with Disabilities (CRPD) calls for an active involvement of all persons with disabilities in decisions that affect them, which illustrates a

shift towards putting the emphasis on participation within policy-making and service provision (United Nations, 2007; Mittler 2015; Löve et al. 2017).

1.1. Aims

Jacobs, MacMahon, and Quayle (2018) identified methodological gaps within existing research on transitions relating to: (1) a focus on parents and the absence of multiple perspectives, even though the transition process involves multiagency decision-making; (2) a lack of involvement of young people; and (3) a lack of focus on transitions as processes.

This study aims to explore: (1) how different individuals make decisions about the young person's transition; (2) how individuals interact and work together; (3) how the young person is involved in the decision-making process; and (4) the systems and frameworks that surround the process.

2. Research process

2.1. Design

The study utilised case-study methodology. Case study research is an in-depth investigation of a contemporary phenomenon within its real-world context (Yin 2002). When the focus of the study is on process and interconnections, the use of different data sources and triangulation during data collection and analysis makes case study research an attractive method (Miles and Huberman 1994; Yin 2002) because researchers are able to follow converging paths of inquiry and look at the phenomena from different angles (Yin 2002; VanWynsberghe and Khan 2007). To be able to allow for an ecological depiction of process including the perspective of multiple stakeholders, inclusive of the young person, a multiple case study design exploring the transition journey of three young people with severe intellectual disability was deemed the most appropriate. Additionally, it was hoped that through the use of different data sources young people would be more present in the research process compared to their involvement in previous studies. The benefits to case studies of involving people with intellectual disability is illustrated well within research on the social history of learning disability, which is largely presented in the form of case studies and narrative accounts of the lives and experiences of individuals, contextualised in their historical context (Mitchell et al. 2006; Atkinson, 2004, 2010; Walmsley and Atkinson 2000).

2.2. Inclusion criteria and recruitment

The research attempted to identify three cases involving: (1) a young person with severe intellectual disability whose life was currently or had recently been affected by the transition from school to adult services (up to two years); (2)

parents and guardians of the young person; and (3) professionals involved in the decision-making process.

Severe intellectual disability was defined by impairments of skills and developmental delay in cognition, language and social abilities, resulting in severe difficulties to adapt to daily demands and social environments. There is thus a high degree of reliance upon others to make decisions on behalf of young people. In the study, parents of two of the young people had applied for guardianship under the Adults with Incapacity (Scotland) Act (2000) and in the third case the young person's parents were exploring it as an option. Guardianship is given where an adult is deemed incapable of making key-decisions about their own welfare and guardians can make decisions on behalf of the person, including decisions about where a person lives and their personal and medical care. However, guardianship does not prevent an involvement of young people in the transition process. The Social Care (Self-directed Support) (Scotland) Act (2013) and National Institute for Health and Care Excellence (NICE) transitions guidelines (2016) provide that the wishes of young people should be central to decision-making processes. This promotes an awareness that young people with severe intellectual disabilities communicate their views and experiences and it highlights the importance of involving in the decision-making process those who know the person best (Simmons and Watson 2014). Exploring how this is achieved in practice is one of the key aims of this study. In the research process we decided to facilitate the involvement of young people by spending time with them and speaking to key people in their lives.

Recruitment of young people and their parents was facilitated by one special needs school and one residential school in two different local authority areas in Scotland. As the schools and organisations knew the backgrounds of the young people well, they assisted in identifying which cases met the inclusion criteria. Purposive sampling was used to identify three families and during initial meetings parents identified other relevant stakeholders in the transition process. Information about the study was subsequently sent out to those persons by post and email.

2.3. Participants

The three young persons involved in each case study will be referred to as Tom, Emma and Peter. An overview of the participants involved in each case is set out below (Table 1).

2.4. Ethics

A detailed protocol was developed which took into account ethical considerations in relation to: (1) the involvement of young people and their incapacity

Table 1. Participants.

	Case 1 (Tom)	Case 2 (Emma)	Case 3 (Peter)
Participants	Young Person (Tom) Mother (3 interviews) Teacher and Head teacher (1 interview) Social worker (1 interview) Adult service transition officer (1 interview) Children-respite key- worker (1 interview) Clinical Psychologist (1 interview) Local authority 1 social care manager (1 interview)	Young person (Emma) Mother (3 interviews) Father (1 interview) Teacher (1 interview) Social worker (2 interviews) Adult service manager (1 interview) Speech and Language therapist (1 interview) Local authority 1 social care manager (1 interview)	Young person (Peter) Mother (2 interviews) Teacher (1 interview) Social worker (1 interview) Adult service senior staff member (1 interview) Adult service admission coordinators (1 interview) Local authority 2 social care manager (1 interview)

to give consent; (2) the sensitivity of the topic and potential issues regarding care of vulnerable children or adults; and (3) the sensitivity of data and anonymity. Details can be obtained from the first author. Ethical approval was given by the NHS Scotland A Research Ethics Committee and the University of Edinburgh. Parents gave consent on behalf of the young people.

2.5. Data collection

The researcher conducted semi-structured interviews and had access to case specific documents that held relevant information about each young person and the transition process. Additionally, the researcher spent time with the young people within their educational and/or adult service settings.

In Tom and Emma’s cases, the researcher followed the transition process as it unfolded and met with their parents three months before the move from school, once the adult service had been identified and after the transition had taken place. Earlier interviews informed later ones as the researcher became more familiar with each case. Peter had transitioned one year previously and data collection involved participants reflecting back on the process.

An overview of the use of each data source in relation to different research questions is given in [Table 2](#).

2.6. Analysis

Emphasising the narrative component of qualitative case study research, a linear approach to understanding the process, following beginning, middle and end, was deemed the most appropriate for this study. In a first instance it appeared crucial to first of all describe each transition process and understand how and why decisions were made. The descriptive insight subsequently informed a deeper exploration of the data across the three cases from an ecological perspective.

Table 2. Research questions.

System	Question	Data sources
Person	How do others see the person with severe ID?	Observations; interviews
Microsystem	How do different stakeholders view the transition process? How are stakeholders involved?	Interviews
Mesosystem	How do stakeholders work together?	Interviews; specific documents
Exosystem	What informs stakeholders' decision?	Interviews; specific documents
Macrosystem	What influences stakeholders' decision-making?	Interviews
Chronosystem	What came BEFORE, what happens NOW, what will happen THEN?	All data sources

2.6.1. Within case analysis

The first step involved the development of timelines and summaries of the transition process for Tom, Emma and Peter (Miles and Huberman 1994; Yin 2002). To create timelines, interview transcripts, field notes and case specific documents were coded to identify events and turning points such as meetings and decisions made using Nvivo11. Some events had specific dates that were used in the timeline (such as review meetings), while other occurrences were processes that had no concrete start and end date but were described as occurring within a weekly or monthly time frame (for example, parents starting to think about the transition at the end of another school term or after a review meeting). The timelines are thus not exact representations but give a very close depiction of the process. Events mentioned by one participant were checked with other participants. The timeline and summary of each transition journey was discussed with mothers during the final interviews (in all cases), social workers (in cases 1 and 2) and adult service staff (case 3) to clarify and validate each timeline.

2.6.2. Cross case synthesis

Framework analysis was used to synthesise findings across the cases and to explore differences and similarities among the three transitions. Framework analysis involves the use of an a-priori framework and using it as the basis to code data (Ritchie and Spencer 1994). We drew on Bronfenbrenner’s (1979) ecological model to better understand the complexity of the transition process. An ecological perspective is helpful to capture interactions and relationships between people who are part of institutional, economic and cultural systems. The ecological model was applied across data sources using Nvivo11. Themes did not fit neatly into separate ecological levels and close relationships between systems were apparent throughout the analysis (for example, conflict between stakeholders seemed to be influenced by cultural and economic factors). Where themes corresponded to different ecological levels, a choice was made as to where the content would fit best (Table 3).

Participants received summaries of their individual interviews and of findings as a whole and were given the opportunity to make comments and request changes.

Table 3. Ecological framework.

Master theme	Subthemes
The young person	Likes and needs Becoming an adult: changes
Microsystems	Family Professional environment Additional networks
Mesosystem	Practical transition Collaborative practice: Concord and Conflict Involvement of young person
Exosystem	Organisational transition Involvement of young person: Parents as advocates Information and Choice
Macrosystem	Culture Politics and economy
Chronosystem	A lifecourse perspective

3. Results

The table below sets out a summary of the transition process for each young person including timelines (Table 4). This is followed by the synthesis across cases using the ecological framework.

3.1. Case synthesis: an ecological perspective

3.1.1. The young person

This theme discusses how far young people's likes and needs informed choices made before questioning how far the move to adult services also marked a step towards adulthood for young people.

3.1.1.1. Likes and needs. Parents favoured adult services able to facilitate activities that young people seemed to enjoy such as being outdoors, engaging in music, arts and crafts and socialising with peers. However, alongside what these young people liked, their vulnerabilities and associated risks were a central part of identifying an adult service placement. This was particularly striking in Tom's case.

Tom's Clinical psychologist: *He does need like high levels of support in terms of sort of helping him to make sense; he needs high levels of structure and routine to help him make sense of the social world and also he has very high levels of sensory need as well.*

3.1.1.2. Becoming an adult: changes. All three young people were described as learning and acquiring new skills. This included getting better at using their communication systems or using the toilet independently. However, young people were also described as becoming physically bigger and this could lead to new challenges for parents. When Emma refused to do something, such as get out of the car, her mother said there was nothing

Table 4. Three transition journeys including timelines.

2014	Family starts to look for information about transition	TOM: Tom is sixteen years old at the beginning of the study. He enjoys art, walks, sensory activities and taking the bus to the local library. Music and watching favourite cartoons and video clips seems important to him, as it does for Emma and Peter. He is diagnosed with autism and severe intellectual disabilities. Tom self-harms, often on a daily basis, and caring for him can be complex. He has two more years at school, but as he is about to turn seventeen he is approaching a transition from respite services for children to respite services for adults. This will result in a significant reduction in respite days. Tom's parents want Tom to continue to live with them but feel that they need sufficient support and respite to be able to do so. There is only one adult respite service in the local authority area that is able to support Tom and offers overnight stays. As a place becomes available at the service for summer for both day and respite care, his parents take the decision for him to leave school one year earlier than had been planned. Its fees are lower than the previously favoured day service and so the budget allows for more respite provision. Additionally, this will mean that Tom accesses one service instead of two, providing greater consistency. The service seems able to meet Tom's needs but in an ideal scenario he would have more time there. The cut in respite provision is a big concern for his family, who worry how it will affect both Tom and the whole family.
Early 2016	Mother visits three local adult services. Finds one service suitable (service B)	
Nov 2016	Transition social worker (SW) allocated	
Dec 2016	Review meeting at school Social work assessment starts	
March 2017	Review meeting at school Conversation with service B about Tom. Service at full capacity with waiting list in place Confirmation of respite transition by the end of summer Senior SW management offers place at service A SW offers placement to parents	
April 2017	Parents accept placement at service A School is informed about Tom leaving this summer School staff prepare transition and contact service A	
May 2017	Service A staff start to shadow Tom at school Service A speaks to parents and children respite about Tom Speech and language joint support for service A staff	
June 2017	Tom begins to visit service A supported by school staff	
July 2017	Tom leaves school and starts at adult service A Clinical psychologist and psychiatrist offer support to service A Meetings to prepare transition from children respite to service A Respite transition and reduction of nights by more than half	
Oct 2017	Transition to adult social work	

(continued)

Table 4. (Continued)

2015	Family starts to find out about adult services within local area	EMMA: Emma is seventeen years old and in her last year of school. She enjoys the company of others and to be part of busy environments engaging in crafts and joining social dance activities. Emma likes singing, music and one of her favourite activities is to blow bubbles. Emma has a diagnosis of autism and severe intellectual disabilities. She is physically very able but depends on other people to prompt her. Emma's parents feel that they are approaching an age where they would like Emma to move into supported accommodation. This has been discussed with her transition social worker but does not seem to be an option at present due to lack of provision. Exploring day service options, her parents would like Emma to go to a local day service that offers workshop-based activities. Its fees are higher than the local authority run day services. To make it possible to fund the day service for five days, her respite allocation is reduced. While the family thought initially they could cope with it, they are finding it increasingly difficult to manage with less respite once Emma leaves school. The wish for supported accommodation remains the main concern for her family.
Aug 2016	Transition social worker (SW) allocated	
Sept 2016	First meeting with parents. Focus on supported accommodation	
Oct 2016	SW told by management accommodation not feasible Parents feel Emma might be too young for accommodation	
Nov 2016	Review meeting at school. Service A supported as day service	
Dec 2016	Children respite stops. No handover to adult respite	
Jan 2017	SW assessment completed. Adult respite service identified Application to Day Service A through SW	
Feb 2017	Start adult respite service No transport to respite provided. Parents refuse to provide it Parents and SW file complaints Transport arranged through school and later SW	
March 2017	Mother and Emma meet Day service A manager	
April 2017	Day service A and SW work out funding for 5 day service Social work ask parents to contribute to 5 day service Parents agree to reduction of respite to fund five days Place at Day service A confirmed for summer Day service A and school exchange information	
May 2017	Emma starts weekly trails at Day service A supported by school Speech and language offer joint support to Day service A	
June 2017	Funding for transport to Day service A in question Transport sorted. Emma shares taxi with other young person Emma finishes school and starts at Day service A	
July 2017		
Sept 2017	Review meeting at Day service. Placement positive Parents voice continued wish for supported accommodation	
Oct 2017	Transition to adult SW	

(continued)

Table 4. (Continued)

Mid 2013	Family bring up transition in review meetings	PETER: Peter is nineteen years old at the start of the study. He is a very active young man and enjoys climbing, cycling and going for hikes. He enjoys food, relaxing and listening to music. He has a diagnosis of autism and severe intellectual disabilities. Peter is physically very able but similarly to Emma, Peter needs other people to prompt him for most day-to-day activities. He has a close relationship with his brother who also has a diagnosis of autism and severe intellectual disabilities. Peter's family live in a rural area of Scotland. Having two children with high support needs was challenging for the family living in a rural area with few local resources. When the family was looking for secondary school placements for their sons, they became aware of a school offering residential placements. Peter and his brother went to live there during term time. The family were very happy with the residential community setting, and want a similar placement for Peter and his brother within adult services. The primary concern for Peter's parents is finding somewhere where their two sons can continue to live together. After one service rescinds their initial offer of two placements, his parents apply to a residential community for young adults three hours' drive away; a place is offered to both boys. The adult community offers placements for young adults up to the age of 25 and his mother is anticipating to start planning for the next transition very soon.
	Parents visit different adult services	
Early 2014	Parents make application to residential adult service A one hour drive away. Brothers names are placed on waiting list	
	Social work supports application and begins assessment	
End 2014	Service A retract their offer of two placements for summer 2016	
	Parents visit different adult services throughout Scotland	
	Parents prefer residential young adult service B 3 hours away	
	Adult social worker becomes involved and resumes assessment	
Sept 2015	Service B admission team visit Peter and his brother at school Meeting at school with parents and service B	
Oct 2015	Two 40-week placements offered by service B	
Early 2016	School, parents and service B start to exchange information	
May 2016	SW funding agreed for both placements	
June 2016	Peter and his brother visit service B supported by school and his parents Parents and service B key staff exchange information and prepare the move	
Aug 2016	Peter and his brother move to service B	

she could do. Peter was described as cycling and walking faster and for longer distances than anyone else in the family and as Tom was becoming older it was more difficult to manage some of his behaviours.

Tom's mother: *When he does kick off now he is six foot nearly so it is a lot harder than when he was ten, so it does become more difficult. That is the irony of it isn't it, you are dealing with someone who is more difficult.*

Participants had different views on how to understand young people's step into adulthood and on how far the transition into adult services should also mark a change in attitudes towards, and expectations of, the young people. Teachers and adult service professionals seemed to see a more central role of choice within adult services and greater flexibility to create activities and timetables that were meeting young people's interests, instead of following the curriculum and meeting the needs of a whole class.

Emma's teacher: *I am not trying to say that adult services don't have structure, but you know, but there is, it's if you are being an adult then you can choose.*

For Emma and Peter, participants emphasised the importance of work activities and practical learning within adult services. All parents emphasised their wish for services to encourage the development of skills, and engagement in activities.

As well as emphasising the importance of meaningful engagement, interviews highlighted tensions between the notion of 'independence', and views of young people continuing to be dependent on adult support. Some professionals connected more independence to the possibility of living in their own flats, fulfilling a step towards 'normal' adulthood, while also describing that to live independently young people would need high levels of support and supervision. Without stable and supportive relationships and environments, a number of participants suggested that young people could easily regress and become more withdrawn. Parents, and some professionals, felt that living in a flat could isolate young people and voiced anxieties about them being dependent on staff and vulnerable to poor quality of care.

Emma's teacher: *I could imagine that she could sit for a very long time if there wasn't that interaction, which I suppose when I think of it, it seems kind of scary.*

Tom's mother: *He is very vulnerable, when someone hurts him he can't tell us.*

Participants described how young people expressed choices and preferences through their behaviour but some described a concern that choices did not always reflect their best interests. This highlighted a tension between notions of choice, independence and responsibilities to support young people to be healthy and engaged.

Peter's adult service: *For me, independence also shows that he is able to show anything what is really him, his choice. What he would like to do. But then that always needs to be guided within the, the necessities of life. I mean that he has the right nutrition and I think there it is important that he still has this, the routine to help him with that.*

Tom's Clinical Psychologist: *I am sure he would like to just be with his family the whole time 'cause he really has a really sort of strong relationships with them, if he had a choice, and not be doing anything in the day but that wouldn't be good for him either as a sort of decision. I think it is good that he is involved.*

3.1.2. Microsystem

The family, education professionals and social care professionals were identified as the young people's main networks. The existence of additional networks, such as friendships or relationships outside the family not including paid employment, were scarce but a number were described and explored within the theme of additional networks.

3.1.2.1. Family. The family was the main and central support system for the young people. Interviews with all stakeholders highlighted close and loving relationships between family members. Parents spoke about their love for and commitment to their child. Needs of parents and children seemed to be closely intertwined and parents described that caring for and advocating on behalf of their children to ensure good quality of care was very demanding at times. Parents were aware of their own aging and how it was impacting on their ability to provide care for their adult children at present and in the future.

Emma's mother: *Because we are getting older I mean I know it is not that old, 57 it is not old but I don't know if we could take another 20 years of it.*

However, it was striking that parental wishes for the transition to adult services in relation to their own needs as carers were always concurrently discussed by parents in light of the likes and needs of young people. Tom's mother hoped for a placement that could provide extensive day and respite services, allowing Tom to live with his family and to provide continuity. In the other two cases, parents reflected on their children still being young adults and wished for an initial young adult placement before considering 'settling their children'. Tom seemed to express through his behaviour that he enjoyed being at home most, while both Emma and Peter enjoyed social interaction and being busy and engaged, reflecting a focus on young people within the choices made by parents.

Tom's mother: *When he gets home, he is quite happy to be home and if we can cope with him at home for now then we will do that until, until we get to that stage where it's not feasible anymore.*

Peter's mother appeared to be the most positive and talked least about the negative impact of having a son with a severe intellectual disability. This might be due to him being the only participant living outside the family, an absence of challenging behaviour and/or him being very content at his current placement. Living in a residential setting did not seem to be connected to less emotional closeness between Peter and his family nor negatively affect communication between staff and parents.

Peter's mother: *I mean I get pictures on Skype and you know they are always doing wonderful things and stuff. And I think yes I mean Peter can't come home and tell me hey mum I climbed a mountain today or drove my bike around the facilities but he is just a smiler and in fact his house produced a book which I need to add to all his others and it is just a photographic testimony of how, what a great year he has had.*

Peter's transition process had occurred a year ago, thus the day-to-day stress of transition was not present at the time of conducting the interviews.

Mothers seemed to play central roles. However, the inclusion of the father's perspective in Emma's case highlighted similar concerns and levels of stress and worries for him to those of mothers.

Emma's father: *I was worried about what was going to happen to her and I was waking up and by the time we got to that meeting I was wiped out, I was completely exhausted.*

Fathers were involved in meeting with professionals and caring for young people at home, but mothers were described as the main carers, with fathers spending more time at work. In all three cases, taking care of their children had impacted on the mothers' ability to sustain a full-time job.

Parents spoke about siblings as providing important relationships for the young people. In all cases, one of the siblings took on a more caring role as they entered young adulthood themselves, which parents stressed was voluntary.

3.1.2.2. Professional environment. Overall, parents spoke positively about the support provided and the care offered to young people within care and education settings. Most participants described consistent and trusting relationships with key members of staff as being important for the young people. There was variation reported in the consistency of relationships: while some professionals had been involved in the young people's lives for more than five years (for example, Peter's teacher, Tom's respite key-worker, Emma's class helper), others had only recently become involved. Staff turnover was mentioned as a problem by both education and adult service professionals.

Health professionals were described as offering important, specialist input, but their direct contact with young people was less than that of education and social care professionals. Social workers' roles differed. They all met

young people in different settings but their contact was described as being mainly with parents.

Peter's mother: *Well social work (...) will only get involved as and when they are needed. They are not actively ringing up to see how he is. So they are invited to reviews or if there is a meeting involving his life at school then they are obviously there.*

3.1.2.3. Additional networks. In all three cases it was difficult for families to draw on the support of their extended family, and the immediate families seemed to draw on different support networks. Other parents with children with disabilities were described as a source of support only in Tom's case. Additionally, a close family friend supported the family in an advocacy role. In Emma's case, one of her paid carers was identified by her mother as someone 'special', who cared about Emma and helped out on occasions. She was described as being like a friend to Emma.

All participants talked about the importance of close relationships generally but only eight mentioned peers and friendships (Tom's adult service and teacher; Emma's mother, teacher and social worker; Peter's mother, adult service senior worker and social worker). There were differences in participants' accounts of the role of peers and friendship. While Emma's social worker and both Emma's and Tom's teachers raised doubts about young people's abilities to form friendships with peers, the eight interviews also included accounts of existing friendships and important interactions with peers.

Tom's adult service: *There is a young man who comes to [our service] who was in Tom's class last year and they seem very friendly it is nice. Tom seems to have sort of a calming effect on [him] and [he] can offer Tom lots of cuddles. Often Tom goes up to [him] for a cuddle, which is lovely. That must be reassuring for them both to come into the service and have a familiar face.*

3.1.3. Mesosystem

3.1.3.1. Practical transition. The practical transition was described as very positive for all three young people, with good communication and sharing of practice among stakeholders.

A disparate health transition to adult mental health services was an issue in Tom's case and was anticipated to happen after the age of 18.

Although parents and professionals did meet at annual or six-monthly review meetings, there was no single meeting where all stakeholders came together. Review meetings at schools seemed to focus on initial plans about possible placements and adult services did not take part in meetings at this stage.

Lack of transport was identified as a potential problem in both Tom's and Emma's cases and while arrangements were made to find a solution by

Tom's social worker, Emma's parents experienced a lengthy struggle to get funding for Emma to travel to both her respite and day service.

Emma's mother: *The stress was unbelievable it was absolutely unbelievable. 'Cause I am prepared to support Emma but I am not prepared to have them take absolutely everything off us.*

The local authority had recently changed their transport policy, asking families to contribute. In both Tom's and Emma's case, transport was ultimately provided by the local authority as cars were shared with other young people accessing the same service.

3.1.3.2. Involvement of the young person. Participants felt that young people had very little involvement in the transition process. This may be because, for participants, choice seemed to be conceptualised as actively verbalising choices, which was not possible for the young people. However, other parts of the interviews illustrated that young people were involved in the practical transition because they expressed how they felt in different environments and communicated their needs through their behaviour. This was taken into account when identifying adult services, making plans about the move and deciding on programs and activities.

All young people started to visit their new adult services before the move and this gave parents and professionals an indication of the suitability of services. Only Peter visited two other similar residential adult services through his school as part of the transition process. Participants described how young people's need for routine and consistency played a central role in this decision. A number of participants (Tom's head teacher and teacher; Emma's social worker; Peter's adult service and social worker) referred to the limitation of only being able to make choices based on knowing young people in their present settings.

Peter's adult service admission: *I mean at that age you have been used to something and you actually manage extremely well and are very happy within that and an alternative of, for example, living in a flat within the community, I mean who is to say whether or not that would be appropriate for him. I wouldn't know. It is based upon how he is just now.*

The move to the new setting was described as positive and all young people seemed to be doing well considering that the transition involved a major change in environment and routine. Young people were described as participating in activities, following their new routines and positively interacting with staff.

3.1.3.3. Collaborative practice: concord and conflict. Parents and professionals seemed to have positive relationships and problems only seemed to relate to limitations such as funding constraints or lack of services. For example, parents were able to differentiate in the interviews between

working with social workers and appreciating their work and effort but feeling frustrated to work with the 'system' they represented.

Emma's mother: *I think the social worker had a really difficult job because her hands were tied, completely tied.*

Social workers and local authority managers reflected on limitations within the system and spoke about their own frustrations.

Local authority manager 2: *Local government in terms of finances get tighter and tighter and tighter, so the message is that we need to do things differently to make sure there is money in the system.*

Social workers and local authority managers made reference to the decision-making process being governed by person-centred practice and approaches. However, references were made simultaneously to constraints within existing budgets and reference was also made to the need 'to share resources with everybody'. All parents showed an understanding of the need to share resources and that there was a limit to the funding available. However, parents argued that the inflexibility to respond to individual situations had the potential to create more expensive packages later on. For example, Tom's mother felt that with more respite they could continue to support Tom at home, and Peter and Emma's parents believed that shared accommodation was not only more beneficial to their children it was also more cost effective than single tenancies.

Tom's mother: *I think there is this ridiculous scenario of the fact that if we said right let him go to a flat you are talking upwards of £200,000 a year to fund that. Whereas we are quite happy for him to stay at home and go to "Adult Service A" everyday but we still feel we need more respite. It is not always joint-up thinking is it?*

While professionals needed to work within existing rules and structures, parents were able to fight and to push against some barriers (for example, Emma's parents succeeding in getting Emma's transport funded by the local authority). The role of parents as advocates for their children will be further explored in the involvement of young people within the exosystem.

3.1.4. Exosystem

3.1.4.1. Organisational transition. Families and young people seemed to have very little involvement in 'wider' decision-making, such as deciding when transition planning should start and being involved in the kind of services available to them. Those decisions seemed to be shaped largely by existing service delivery and available budgets.

It seemed that everyone, from parents to social workers and local authority management, felt that their possibilities were limited by strategy and budget decisions that were made 'higher' and which they were unable to influence.

Local authority manager 1: *The budgets are made in Westminster or they are made down in Holyrood [UK and Scottish parliaments]. (...) If it continues to decrease it will present us with, well it already is presenting us with real challenges going forward. I don't have the answer to that question yet.*

Emma's social worker: *We are more in a corporate sort of world and environment and it is, if you are an old school social worker like me it is really not great (...) if you feel like you are fighting a system.*

Adult service providers reflected on their dependency on having agreed funding in place before being able to recruit staff and plan the transition. Furthermore, the high demand they experienced also resulted in them being dependent on current service-users moving on and having their funding confirmed.

3.1.4.2. Information, resources and available services. In all three cases, parents started to think about and plan the transition two to three years in advance. Parents felt that there had been little information and support available from professionals at those early stages and parents relied on themselves to find out about available services.

Parents and professionals described a lack of local services for young people with high dependency and complex needs and that existing services seemed to operate at full capacity. Tom and Emma lived in a local authority area with a relatively greater choice of services, yet there appeared to be a lack of services for those with complex healthcare needs and challenging behaviour.

Tom's social worker: *There is a lack of support services for people with complex behavioural needs absolutely. Complex personal care needs absolutely.*

Parents and professionals preferred local services, as this enabled young people to stay close to their families. Yet, there was an awareness that local services were not always able to meet people's needs. This resulted in an out-of-area placement in Peter's case.

LA Manager 2: *I think providers can still be quite reluctant to go down that way. For real high dependency you need a very, very specialised kind of resource and as I say that is why you have difficulties.*

For Emma there seemed to be more choices, but her parents experienced a lack of 'meaningful' services, as they did not want a 'babysitting' service. In her case, the family's preferred service was more expensive and not covered by the allocated budget resulting in a decrease in respite for Emma and her family.

3.1.4.3. Involvement of the young person: parents as advocates. The extent to which young people were involved in the decision-making process at an organisational level was difficult to conceptualise. In all three cases

parents were strong advocates on behalf of their children and were able to put their concerns forward. However, although individual concerns and wishes were able to be expressed by both parents and professionals, this did not necessarily lead to any changed outcomes. For example, Tom's severity of need was acknowledged by everyone and education and health professionals voiced their concerns about the respite reduction. This seemed to have an influence on a placement being offered to Tom in the local authority run day and respite service, which had limited spaces, but his respite allowance still reduced significantly. In Emma's case, everyone who knew her well talked about Emma showing through her behaviour that she was ready to live outside her family and although this was highlighted in her social work assessment, it did not seem to be an option in the near future due to a lack of accommodation services. Within the exosystem, available resources seemed to shape the process to a large extent.

Fighting for young people and their own right for support caused stress for parents.

Emma's mother: *I mean it is not about the money it is about the principle I think. But every little step brings more problems with it, if you know what I mean, because it is just another anxiety and they know that, so they know that people will get fed up with fighting.*

3.1.5. Macrosystem

3.1.5.1. Culture. Parents and professionals made references to their experiences of changes within the culture and values of service delivery and attitudes to those with intellectual disabilities in society over past decades. The move away from segregated settings was described as a significant shift in the care and inclusion of people with severe intellectual disabilities in society. However, parents and some professionals (all education professionals, Peter's adult service and Emma's social worker) discussed how they felt that the closure of day services and funding cuts since the beginning of austerity had resulted in a decrease in the number of possibilities for people with severe learning disabilities and that policy values such as inclusion, choice and person-centeredness were not reflected in the services and resources available to families.

Peter's adult service admission: *The difference between the reality and what is being presented and what is said has never been as wide as it is now ever since I am involved in this work and that is forever. So I have never known a time like this. I think it is really, really desperate*

Involvement and engagement within local communities were important for those that knew the young people well, but especially parents and adult service staff who highlighted the importance of meaningful inclusion in contrast to 'babysitting'. Art, music and workshop-based activities were

mentioned as good examples of how to achieve meaning within activities. Access to nature and to public facilities, such as libraries or sport activities, were cited as other examples.

Emma's mother: *I don't want to see her wandering around with some carers on the phone (...) to get something to eat. I want her stimulated.*

3.1.5.2. Politics and economy. National policies, promoting person-centeredness and individualisation, seemed to describe 'the ideal scenario', while local authority documents and interviews with managers pointed more to limits within service delivery, describing a shift towards providing fewer services. There thus seemed to be a tension between conceptualising choice as what families ideally liked and choices being inherently linked to what was available. For example, in Emma's and Tom's cases, parents were told that choosing a more expensive service would involve a decrease in respite services. Parents therefore talked about how their choices felt limited, while local authority managers described that it was families who ultimately made the choice as to what they would like.

Tom's mother: *I didn't feel there was any room for manoeuvre at all. Sadly.*

LA manager 1: *So basically if they can do it for five days at that provider but they want five days with this provider, which they can't afford, sorry that is your choice.*

In both Tom's and Emma's cases, the local authority respite policy played a role in the decision-making process. Both young people transitioned to adult respite service on their 17th birthday and not at the end of their school years, leading to difficulties as families were faced with two disparate transitions (from school to adult services, and from child to adult respite). Both families experienced a decrease in support within adult respite services, with Tom's family experiencing a significant drop. A decrease of respite support in adult services, while needs of the young people remained high, was incomprehensible for parents.

3.1.6. Chronosystem

3.1.6.1. A life course perspective. Narratives of parents were framed within reflections of past experiences, going back to their children's diagnosis and early education experiences, and in anticipation of the far future and worries about their own aging.

What stood out in the transitions of all three young people was that, after the transitions, many questions and concerns about the nearer future for their children remained for parents. In interviews with parents, once the transition to the new adult service was made, issues and questions that had concerned parents in the beginning of the present transition started to be raised again and parents talked about a lack of information on what would

happen next. In Peter's case, his placement was coming to an end at the age of 25 and issues were raised around a lack of local services. Emma's parents were still looking for a placement outside the family but were anxious that this should not impact on her being able to access her day service. Tom's mother hoped to have found the right place for Tom to settle but wondered what would happen if she found the family was not coping with the reduced respite. Losing the involvement of the transition social worker and not having a new named person worried her.

Tom's mother: *If we decide in six months he is not, we are not getting enough respite, where do we go then? Apart from having a nervous breakdown and ending up in [the mental health hospital]?*

While all participants reflected on the near adult future of young people, parents were the only ones who explicitly talked about the transition in terms of planning for a time when they would no longer be able to look after, or advocate on behalf of, their children.

Tom's mother: *What will happen when we are dead is my main concern. Who will look after him? Will he be happy? Will he have a fulfilled life?*

4. Discussion

This study highlights concerns about the transition that have been identified by others, specifically the lack of early planning and information for parents (Hardy 2005; Cox 2017); tensions between an understanding of the transition as an event from one service to another within the organisational context and families asking for a whole life-course understanding (Jindal-Snape 2016); and a widening gap between ideal-led policies and resource-led practice at times of austerity (Mansell and Beadle-Brown 2004; Roulstone and Morgan 2009). While increasing attention has been paid to the topic of transitions over past decades there seems to be little improvement in them.

This study was able to add to existing findings through a focus on multiple perspectives and processes within an ecological model. Tensions were identified within and across ecological levels, namely differences in the involvement of young people within the Meso- and Exosystem; and striving for independence while emphasising the need for consistent support networks for young people throughout their lives. Using an ecological model helped us to make a distinction between the 'practical transition' (Mesosystem) and the 'organisational transition' (Exosystem). Young people moving from school to a new setting described a more practical transition, while decisions in relation to funding and access to services related to structural processes that began earlier and continued after the move. It is suggested that the involvement of the young person differs between practical and organisational processes, between young people's Micro- and

Mesosystems and their Exo- and Macrosystem, as has been suggested in literature on healthcare transitions (Care Quality Commission 2014; NIC).

Focussing on the transition as a process helped to map where key decisions were made and what influenced them. Available resources played a central role in identifying the service provider and the amount of support available to families. Additionally, funding and availability of services influenced the timing of the transition. For example, Tom left school one year earlier than had been anticipated and in Peter's case, although his placement had been agreed almost a year in advance, details about his exact placement at his present adult service could only be confirmed three months before the move, once current service-users were identified as 'moving on'.

Within the practical transition there seemed to be a stronger emphasis on the involvement of young people. It seemed that young people's needs and behaviour within their immediate environments influenced decisions that were made to some extent. Young people communicated their needs and likes or dislikes through their behaviour, for example by refusing to do an activity, by showing signs of distress or by showing their enjoyment through laughing and increased levels of interaction. At the same time, the study highlighted familiar complexities in interpreting young people's behaviours and tensions between 'choice' and 'best-interests' (Dunn et al. 2007; Ferguson, Jarrett, and Terras 2011). Translating young people's preferences and actions into views requires a level of interpretation but a collective approach seemed to help those that knew young people well to collectively negotiate their views and preferences and to facilitate their involvement within the practical move. Similarly, Simmons and Watson (2014) describe that a collective approach to 'meaning-making' can facilitate the inclusion of young people. Using an ecological model illustrated how the wishes and needs of young people, as identified by those close to them, could not always be met due to a lack of available resources and organisational barriers within the Exosystem.

Involving the perspectives of different stakeholders highlighted differences in conceptualisations of the transition as a step towards adulthood. There seemed to be differences between conceptualisations of independence as an absence of support, compared to a more a relational understanding that valued consistent and supportive relationships in young people's lives. The interdependence of families and institutions is particularly significant in the context of severe intellectual disabilities (Pilnick et al. 2011; Young 2001). Interdependence emphasises the importance of social networks and resources to support young people throughout their life journey, as well as emphasising the agency young people have within their relationships instead of seeing them as passive and merely dependent. This study adds to a growing awareness that the concept of interdependence might be more valuable

than independence or dependence (Hogg 1999; Young 2001). We suggest that it can help to understand the attainment of adulthood from a relational perspective that bridges dichotomies between independence and dependence. Grove (2012) argues that an inquiry into interdependence is of particular interest when examining the lives of people with severe or profound intellectual disabilities to develop “(...) *an ethic of social inclusion that promotes interpersonal interaction and relationships as the fundamental mechanism of achieving social inclusion*” (p. 346).

The interdependence of the decision-making process lies at the heart of this study. Our findings suggest that if those close to young people are attuned and receptive to the young people's communication, they are able to advocate on their behalf. Yet, this also highlights the vulnerability of young people who do not have closely involved families as advocates. Individuals with severe or profound intellectual disability have little influence over their social networks and the family often remains the individuals' main and only social network outside of professionals (Wilder 2008; Kamstra et al. 2015). Moreover, high staff turnover in both social care and social work further contribute to this problem (Skills for Care 2017; Moritay, Manthorpe, and Harris 2018).

The involvement of professionals in the study highlighted how all stakeholders felt that their choices were limited by available resources. Not only named stakeholders played a role, but ‘the system’ emerged as an actor. This seemed to be a dubious actor, referred to as ‘government’, ‘budgets’, ‘higher up’, ‘corporate world’ or ‘money’. Similarly, Altermark (2018) describes that ‘the opponents’ disabled people are faced with might not be actors or groups but systems and ideologies.

4.1. Limitations

This study is based on three cases, giving a picture of three different transition experiences. Understandably, findings need to be understood within the context of each case but we argue that there is high value in presenting stories able to highlight difficulties faced by those at the core, as have others (Lenehan 2017; Cox 2017).

Parents in this study were all proactive and able to advocate on behalf of their children. The study demonstrated the challenges for researchers to access views of parents who experience greater levels of conflict and who might feel less able to take on strong advocacy roles.

5. Conclusion

The CRPD (United Nations, 2007) promotes participation of persons with disabilities in all matters including policymaking and service commissioning.

Our study suggests that while families and young people are involved within practical decision-making there continues to be a need to improve participation across all levels. Our study highlights a lack of involvement of young people within the organisational sphere despite a call for inclusion within policies and international agreements. This is mirrored within the involvement of young people in research. Few studies focus on those with severe or profound intellectual disabilities, and even fewer involve the person in the research process (Nind 2008; Jacobs, MacMahon, and Quayle 2018). Studies are typically concerned with interventions and there is a lack of studies that provide a detailed understanding of the lives of people with severe or profound intellectual disabilities. This reflects persisting assumptions that view people with severe intellectual disabilities as passive (Simmons and Watson 2014). This study aimed to have a stronger involvement of young people. The attempt to include an account of young people's lives and experiences relied on the accounts of others, focusing on young people within interviews, accessing personal plans and spending time with young people. The inclusion of multiple perspectives enriched the data in relation to young people and spending time with young people helped us as researchers to understand the importance of knowing about the person's everyday life. Detailed knowledge of young people's everyday lives was present within the Micro- and Mesosystem, while there seemed to be less of a connection between knowing about young people's lives and influences and decisions made within the Exo- and Macrosystem. Detailed knowledge about everyday life experiences has been suggested by others as a way to facilitate participation of marginalised groups within research, policy making and service commissioning and to bridge the gap between policy and practice (Löve et al. 2017; Smith 1990).

To facilitate an involvement that is based on detailed knowledge of people's everyday life experiences requires time (Ward and Stewart 2008) and to work closely within collaborative teams. Our study echoes best practice guidelines that recommend that planning should be available from age 14 and should continue to at least age 25 (Scottish Transitions Forum 2017). Yet the needs and preferences of young people will change throughout adulthood, which requires ongoing collaboration between families and professionals to be able to plan for future changes. Careful thought needs to be given where there are concerns about the continuity of professional involvement to ensure that detailed information is recorded and passed on and that families do not feel left alone once the transition to adult services has been completed.

Additionally, our study emphasises the importance of the wider service provision context. Specifically, this study highlights the importance of meaningful activities for young people within adulthood, as have others (Mietola et al.

2017; Mietola and Vehmas 2018; Haddow 2004). Involving families in the process of service commissioning appears crucial to explore what meaningful services can look like.

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'Making narrative portraits: a methodological approach to analysing qualitative data'

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ABSTRACT

This paper proposes the method of 'narrative portraiture', which, located within the wider field of narrative studies, offers an analytical tool to narrative data. Two research projects, one on disability and one on identity, are used to illustrate how the method can be applied. While the paper will focus on the methodological benefits and limitations of the approach, throughout the article we also highlight the ethical concern of representation. We suggest that through 'narrative portraiture' research findings can be contextualised in broader social narratives without losing sight of the unique personal qualities of the research encounter. Thus, we argue for the importance of bringing the participant and their everyday life experience into focus, highlighting that a portrayal of a sole story can be, not only a medium to understand a research phenomenon, but also a valuable research output in itself.

KEYWORDS

Narrative; data analysis; qualitative; stories; ethics

Introduction

Many researchers who work with qualitative data end up with numerous pages of written material, which can make it difficult to know where to start. In this paper, we propose an analytical approach to working qualitatively with data emerging from interviews, focus groups, observations, or other sources that involve people's narratives. The method, which we call 'narrative portraiture', can be complementary to thematic approaches as it helps researchers to engage with qualitative data at different stages of the analytic process. We suggest that it is a helpful technique to employ at the beginning of the analytic process, aiding the researcher to form an in-depth understanding of each participant's or case's story. Conversely, if the data analysis has concluded or is near to an end, it offers a means to enhance the presentation of research findings and honour participants' stories.

Strengths of narrative approaches

Thematic approaches to data analysis have been criticised for ignoring context and differences between individual accounts (Ayres, Kavanaugh, & Knafl, 2003). While interview and text sequences are coded and recoded into smaller units, their meaning can be decontextualised because categories instead of process frame the analysis. Maxwell (2012) argues that in such 'similarity based' analysis, categories start to replace the original connected data structure. Thus, one of the dangers with categorical coding is that it threatens 'the local web of causality' (Miles

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& Huberman, 1994, p. 151). Narrative approaches, on the other hand, work closely with context. Maxwell (2012) identifies them as ‘contiguity based’. While thematic approaches would look at abstract connections across people’s lives, they risk losing the person’s individual stories in the process. Contiguity based approaches stay with the same person or process throughout. Through the methodological approach we present in this paper, we attempt to understand individuals and specific processes. However, we suggest viewing thematic approaches and narrative approaches not as incompatible, but rather as complementary to one another. They are helpful to answer different questions during the research process and can feed from and into each other.

Whilst qualitative studies have been dominated by thematic approaches to data analysis (Mitchell & Egudo, 2003), narrative has always had theoretical relevance in social sciences (Bruner, 1991, 2004; Gottschall & Wilson, 2005; McAdams, 1997; Ricoeur, 1991) and recently it has become more popular within qualitative research from a methodological perspective in disciplines such as psychology and psychoanalysis (Freeman, 2007; Seidman, 2006), anthropology (Scutt & Hobson, 2013), sociology (Frank, 1994; Maines, 1993), and organizational science (Abma, 2003; Beech, 2000).

Narrative approaches explore how people make sense of their experiences (Riessman, 2008), as well as seeing stories as a powerful medium to communicate information (Gottschall & Wilson, 2005; Mitchell & Egudo, 2003). Examples of narrative approaches concerned with meaning-making are, amongst others, narrative inquiry (McAdams, 2008; Speedy, 2005), narrative profiles (Seidman, 2006), narrative ethics (Frank, 2014), narrative analysis (Gee, 1986; Gee & Grosjean, 1984), and narratology (Todorov, 1971). Other approaches focus on stories as a powerful way to present and transform textual data such as writing as a method of inquiry (Richardson & St. Pierre, 2005), autoethnography (Ellis, Adams, & Bochner, 2011), and poetic inquiry (Butler-Kisber, 2017).

Within the field of narrative, some approaches analyse discourse (Arribas-Ayllon & Walkerdine, 2008; Georgakopoulou & Goutsos, 2004) and voice used (Gilligan, Spencer, Weinberg, & Bertsch, 2003; Woodcock, 2005), which leads to an abstract focus on knowledge construction. We argue that people’s narratives have ontological relevance in themselves and that there is value in attempting to write about and reflect ‘the ordinary lives of people’ (Shakespeare, 2014, p. 52) and in staying closely with the research experience. We turned to narrative as it helps researchers to embed social meaning in the concrete, particular doings of people (Erickson, 1977; Flyvbjerg, 2006). As Ken Plummer (1995) states, individuals tell stories, which are not only personal, but which form part of larger situational, organisational, cultural, and historical narratives. Narrative puts the personal and the social in the same space; in an overlapping, intricate relationship (Speedy, 2008). Narrative portraiture can add to the existing field of narrative research because, by staying close to the raw data, we bring the participants back to the centre of the research. Our approach aims to use narrative to build a bridge between participants, researchers, and audience by communicating people’s experiences more directly.

In this paper we will illustrate how we used narrative portraiture in two separate research projects by discussing two examples of narrative portraits constructed from (i) in-depth interviews relating to individual participants; and (ii) data from case studies involving interviews, observations and documents. We will offer some guidelines for other researchers to apply this approach to their own research. We also emphasise the need to pay attention to the inevitable ethical tensions that emerge when working with people’s narratives and sensitive data.

We refer to ‘narrative’ as a more encompassing term that explores how people make sense of life through the act of narrating. Narratives can refer to personal, family, national, cultural, social, or historic domains (Bruner, 1986; McAdams, 1997). When using the term ‘story’, we mean a smaller unit (traditionally understood with a beginning, middle, and end) that can be contained within a greater cultural, social, or personal narrative (Georgakopoulou, 2007; Gottschall & Wilson, 2005; Plummer, 1995).

A proposition for narrative portraiture

Narrative portraiture acknowledges that researchers have certain knowledge of the phenomenon under investigation – which is informed by the literature and their scholarship – but we believe that there needs to be more space given to the actual stories people tell about their own lives. In doing so, narrative portraiture becomes a decolonial methodology because it disrupts the common research practice of privileging the researcher's interpretation and over-analysing people's narratives. As any other method, narrative portraiture still reflects the standpoint of the inquirer, but it aims to make transparent its process and present a product in which the participant is visible and cognisable. By selecting and rearranging extracts from interviews, observations, field notes, or documents, we create portraits that offer a glimpse into the subjects' lives. The portraits align with life story research (Etherington, 2009; McAdams, 2008), in-depth case study research (Flyvbjerg, 2006), narrative profiles (Seidman, 2006), structural narrative analysis (Labov & Waletzky, 1997) and, by doing so, the method captures rich material that often escapes the scope of other forms of analysis. Narrative portraits depict social phenomena through people's stories of everyday life experience. They are thus able to bridge the gap between individual and society. Furthermore, the use of portraits showed us that research findings, at least in the two research fields in which we were working, are often 'hidden' in areas of participants' lives that might not be associated with the main focus of our research questions. We suggest that our narrative approach helps to capture contextual nuances that are otherwise often overlooked.

We want to highlight that this method does not aim to produce accurate realities; instead, we present narrative portraiture as a methodological tool that aims to reflect, interpret, and communicate narrated experiences. We strive to respect voices by working only with the structure of the text – what comes first, what comes next, what comes after that – to allow the text to read fluently and easily. The depictions are therefore the participants' narratives but still our editorial work reflects a negotiation between their narrative identities (McAdams, 1997) – that is, how they see themselves and how they tell their stories – and more relational identities (Anderson, 2012b) – that is, what they decided to share with us, what they projected to us, and what we imposed onto them. With these negotiations in mind, we crafted our portraits by collating memorable passages of our data. We believe that a personal way of approaching people's narratives is not only important but also necessary, especially in cases where power has been disproportionately unbalanced and where voices have been silenced. Mignolo (2009) writes that in the politics of knowledge, 'bio-graphical configurations' determine who is and who is not allowed to create knowledge. He urges to call into question the principles and practices that maintain hierarchies of power in the production of knowledge. In this case, through narrative portraiture, we aim to leave participants' narratives mostly uninterpreted as an acknowledgement of their expertise on their own lives. The portraits are presented at length in an attempt to show that people's stories are worth listening to. This deliberate emphasis on moving away from abstract interpretations does not equate a lack of analysis. We believe that analysis can come in the form of a detailed, systematic, and structural examination of people's narrative to then arrange it into what we call a narrative portrait: a rich and expressive first-person account in which participants voices prevail.

The process of making narrative portraits

Narrative portraiture is helpful in answering research questions that: (a) are concerned with context and relationality; and (b) aim to capture processes in detail. These qualities allow researchers to engage with crucial aspects of research, such as ambiguity and change, within personal narratives. We tailored our analysis method aided by a combination of Labov's and Waletzky's (Labov, 1972; Labov & Waletzky, 1997) structural approach to narratives; case study research (Flyvbjerg, 2006; Miles & Huberman, 1994; Yin, 2014); life story research (Riessman, 2008; Walmsley, 1995); and Dan McAdams' analytical devices for personal narratives (McAdams & Bowman, 2001; McAdams

& Guo, 2014). We complemented these analytic approaches with a series of theory-driven analytical features that helped us to identify aspects that were specific to our research topics, in Edgar’s case these were (1) the erotic; (2) romantic relationships; and (3) their intertwinements with identity processes, whilst in Paula’s case these were the identification of key influences in decision-making processes from an ecological perspective. Table 1 shows this tailored method and the specific questions and key words that can be derived from them.

Using a narrative approach might appear to the outsider to involve little analytic know-how, being merely a representation of the data. But we believe that developing a coherent narrative from vast amounts of qualitative data requires skill and can be approached in a methodical manner.

The analytic strategy we propose fulfils two tasks: first, it offers a detailed description of the story, illustrating process and context (the ‘how’); and, secondly, it provides an indication of underlying reasons and influences (the ‘why’).

The analytic steps suggested by us involve coding for: (1) Characters; (2) Time; (3) Space and Circumstances; (4) Key Events; and (5) Intersection of phenomena of interest. The tools in table 1 can be used as a guide to start the analytic process.

An in-depth account of what happened when, where, and with whom might seem very descriptive. However, in the first instance, before interpreting and explaining the data, it is useful to write a holistic description, outlining the story or stories. The descriptive insight can then subsequently inform a deeper exploration of the data to explore questions of ‘why’ (Yin, 2014).

Application of narrative portraiture in two projects

In this section, our aim is to explain how this narrative analysis method looks in practice. Each author will draw on their PhD projects and describe their experiences of using the approach. Due to the sensitive data that was generated, the information we represent here has been crafted into composites that aim to illustrate the method rather than focus on personal details.

Narrative portraiture in a project on gay men’s identities – Edgar Rodríguez-Dorans

In my doctoral research, I explored the contributions that sexual, erotic, and romantic connections make to gay men’s sense of identity (Rodríguez-Dorans, 2018). I was interested in understanding what these relationships mean to gay men. To conduct this study, I interviewed ten gay men of different ages and backgrounds living in the United Kingdom, each of whom provided narrative data during unstructured one-to-one, one-off interviews. Drawing upon a narrative structural analysis, I analysed my findings in two ways: first in the form of idiographic narratives and, secondly, as an overarching analysis with central themes identified across participants’ narratives.

Table 1. Analytic tools to aid the process of making narrative portraits.

Codes	Research Question *helps to illustrate	Key-words: What to look for
Characters	WHO – Important characters; Relationships between characters	Names, pronouns, the first person ('I'), experiences or events involving other people
Time	WHEN – Historic context; Sequence of story; Experience of time	Dates, Years, Conjunctions of time (after, before, when ...), Time periods (weeks, months, days)
Space	WHERE – Geography; Political, cultural, social, economic context	Macro-geography (cities, countries, continents), Micro-space (across the road, in the kitchen, at the hospital), virtual spaces (online, state of mind, an emotional space)
Key-events	HOW/WHY – Connections and Relations; Interactions; Turning points; Wider influences	Strong emotions surrounding event, Link to important decision that is made, Change in narrative after event
Phenomena of interest	HOW/WHY – How is phenomena of interest narrated, conceptualised, experienced; Where is phenomena of interest located; Intersection of concepts and context	Pre-identified themes of interest e.g. ecological perspective, identity, disability ...

One of my first thoughts while transcribing was to produce a summary of the participants' stories in order to reflect my impressions about them and introduce them to the reader by means of the third person voice. The use of the third person voice to describe and interpret participants' narratives made me realise that this practice was reproducing the dynamics that many of these participants had experienced throughout their lives: others have analysed, questioned, and determined the soundness, logic, and validity of their relationships, their identities, and their very own existence. As members of a population that has faced numerous challenges, many gay men have learnt to live in secret; to not disclose their identities at school, in the workplace; to conceal their erotic desires with friends, families; and some have concluded that their stories belong at the margins of society. That realisation made me work on a method that would allow me to use participants' own words. The use of participants' own words started to show methodological potential in the sense that it was representing knowledgeable, empowered, dignified individuals who knew about their lives and were creating meanings around their experiences without much interpretation from my 'expert' researcher's view. This observation made me rethink the function of my data analysis and renegotiate the balance between interpreting participants' narratives and listening whilst trying to uphold the view that they are the experts on their own lives (Anderson, 2012a). This methodological attempt to balance the power between the researcher's role in interpreting the data and the participant's expertise in their lived experience is what I called 'narrative portraits'.

Narrative conversations in a project of transition processes in the lives of young people with severe intellectual disability – Paula Jacobs

As part of my PhD, I explored how decisions are made for and with young people with severe intellectual disability who are moving from education to adult services (Jacobs, MacMahon, & Quayle, 2019). I was interested in how those involved make their decisions, how external influences shape the transition process and how young people themselves were involved. I was looking for an approach to narrative that could illustrate people interacting within their social, cultural, and economic spheres. During the data collection process, I followed three young people with severe learning disabilities, their parents, and professionals involved through the journey from school to adult services. This involved interviews with parents and professionals at different points in time; spending time with young people; and reviewing relevant documents. When I came to the analysis I struggled to find a way to include the perspective of the young person. As all three young people were mostly non-verbal, I needed to think differently about including their 'voice'. This led me to narrative as a way to give a glimpse into the life of the person, a life that seemed largely dependent on decisions made by others, organisational structures and resources available within local authorities. I decided to use my interviews with those that were close to the young person, my observations and own reflections to craft what I called 'narrative conversations' to give an in-depth account of the transition process and the everyday life experiences of the young people and their families. I had noticed how certain elements of my data seemed to be 'talking' to each other. In interviews, for example, people were referring to the same events and key decisions. I started by using timelines (Yin, 2014) and by mapping the decision-making process across time, before developing narrative conversations using participants' own words to reflect on key-events that I had identified in the timeline of each transition process, as well as using my observations to reflect on the involvement of the young person.

In the end, each case was introduced by a summary of the transition written from the perspective of the narrator (me). The summary was followed by the timeline and an introduction of key-actors, their roles and relationships. Figure 1 shows an example timeline and how interview extracts were connected to identify key-events during the analysis (for example, 'the respite transition'). The final write-up included a narrative that followed the timeline. I used the identified key-events as headings to introduce steps within the decision-process, followed by extracts from interviews, which illustrated different people's perspectives and reflections on the process. I weaved in my own narrative

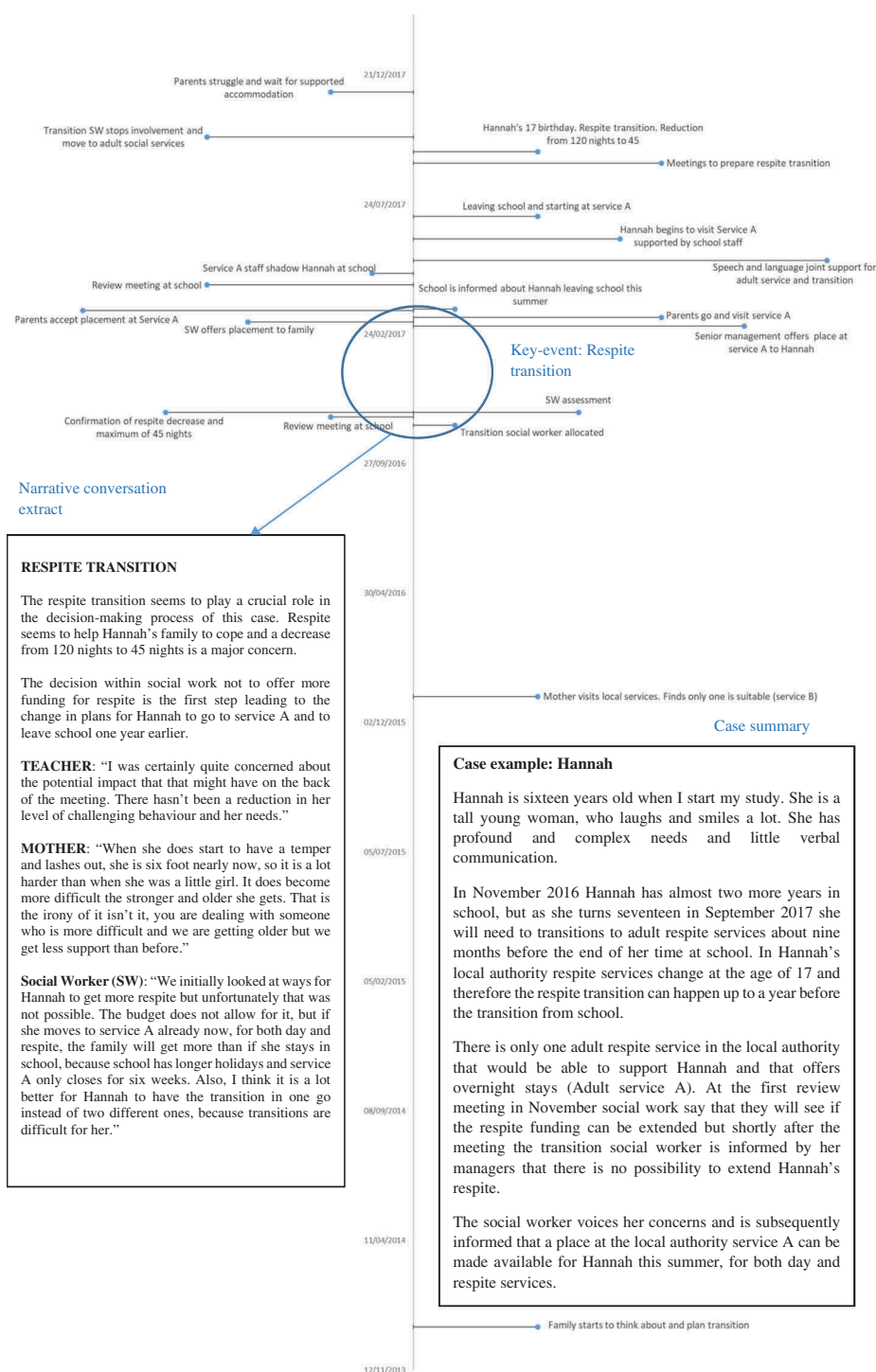


Figure 1. Development of timeline and 'narrative conversations'.

between interview extracts, including vignettes from my encounters with the young people and reflections on the processes from my observations and field notes. Being able to incorporate observations and interview extracts showed how young people were influencing the process to

some extent through their behaviour in their immediate environments. The narrative conversations read like a play and this led me to record an audio play based on a composite case, which was made available to the public and shared by third sector organisations (see Jacobs, 2019). Narrative portraiture enabled me to communicate how the transition experience is like for young people and their families and it challenged my own views of young people as merely passive within the process.

Having contextualised the two projects that originated this method, we will now look more closely at the five analytic steps that we propose as a guideline for the narrative portraiture.

Characters. For researchers interested in interpersonal or relational phenomena, it is crucial to identify the characters in participants' stories, as they will become an essential part of the data analysis. The first step in this method of narrative portraiture consists of 'colour-marking' the text, which can be done with electronic or hard copies of the transcriptions. Using colour that is consistent across all transcripts helps to have a quickly identifiable visual cue. As seen in Figure 2, the text highlighted in blue indicates all the people who are present in the narration. Characters can be present in the story explicitly or implicitly. For example, in the research on gay men's identities, participants often talked about 'sexual experiences', which implies another person in addition to the teller. The 'sexual experience' is therefore colour-marked in blue, as it implies the presence of a 'hidden' character. This first step in the narrative portraiture method equates the location of characters in terms of Labov and Waletzky's guidelines (1997). Further analysis will benefit from categorising the participant as the protagonist, and other characters as main, secondary, unfolding or incidental characters.

Time. The second analytic step we suggest is to take a linear approach to understanding process, although this is not the only possibility. Linear approaches can be problematic because a sequenced structure is applied to people's lives, when life can often be rather chaotic and formless (A. Frank, 1994). When developing stories, researchers should try to capture the way in which the stories were told to them and some narratives might not follow a linear pattern (Goldstein, 2012). For examples of 'chaotic' narratives, see Frank (1994). Additionally, when exploring processes involving different people and when trying to capture macro influences, timelines might need to have different layers. Timelines can thus be simple or complex, involving diverging paths and gaps. To develop timelines, interview transcripts, field notes or documents can be coded looking for references to time and identifying relevant events, actions or experiences. To create timelines, researchers might want to use visual displays using software such as Microsoft Excel or Adobe Illustrator.

The timescale can be as short as the immediate past (moments ago) to a longer scale (years ago). A sense of time is identifiable when participants state it overtly through sentences such as: *'I was 20'*, *'I haven't spoken to my mum in 15 years'*, or it can also be more implicit, *'when I was studying at Manchester University'*, which can only be put in a timeframe in the context of the narrative as a whole.

Orientation in space and circumstances. The next step in the narrative portraiture method invites researchers to identify the 'orientation signs' (Labov & Waletzky, 1997). To do this, we suggest colour-marking – green in Figure 2 – all the sentences that orient the story in space and circumstances. 'Space' can be understood as macro-geography (cities, countries, continents), as micro-space (a bedroom, a desk, across the road), or it can be a virtual space (online, a state of mind, an emotional space). This part of the process constitutes a mapping process that can be very clear as in *'we came to Manchester'* or *'he lived 300 miles away'*. In the second sentence the implication of *'300 miles away'* gives us a different quality that needs to be analysed in the context of the whole story.

Key events/turning points. Going back to the storyline, we now suggest identifying key events and turning points. The storylines will include various events or actions but not all of them will stand



-  Characters – explicit and implicit in the narrative.
-  Orientation in space and circumstances.
-  Special narrative features particular to the project – erotic content.
-  Special narrative features particular to the project – romantic content.
-  Special narrative features particular to the project – the self has a crisis.

Figure 2. Example of the colour-coding and narrative process in narrative portraiture.

out or help with understanding the 'why' within the research question. Key events might relate to important relationships, changes in people's lifestyle, inner and outer changes, and individual or external influences (such as the introduction of new legislation, economic or political change, an

illness, a change in perspective, or losing a close friend). Within this process, it becomes important to keep an awareness on how internal and external influences interact; this will help with developing a holistic and in-depth understanding of the interdependence of individuals and their environments moving through time.

Intersection of phenomena. Often researchers in social science look for complex phenomena that involve three or more concepts, aspects, or factors. When working with complex narrative data, we suggest looking at this intertwinement of concepts by locating how they operate separately in the narrative and mapping them in the same way as the characters and orientation in space and circumstances. The task requires operationalising these concepts according to the theoretical framework of the research. For example, in the research on gay men's identities the three concepts that needed to be operationalised were 'identity', 'erotic' and 'romantic' relationships. In this case, the theoretical framework brought to light that 'identity' often comes across in the narrative when the individual is in crisis (Lawler, 2014), therefore, it was crucial to locate – and colour-mark – those episodes of crisis in the narration.

In Figure 2, romantic moments have been identified as they are coloured in yellow, erotic moments have been highlighted in pink, and episodes of identity crises are identified with a stormy cloud. With these elements mapped out, the coloured and signalled text provides a visual indicator of the intersection of the three concepts. This intersection constitutes a core feature of the narrative portraiture method as it offers the opportunity to locate complex concepts that are often difficult to pin down. An example of a narrative portrait derived from this method can be seen through the story of Gustav, a man whose narrative of 'not being properly gay' demonstrates the complexity of some people's narratives and the need to show those intricate qualities (see Rodriguez-Dorans, 2020).

Discussion

Narrative portraiture offers a political shift towards focusing on people rather than on abstract results. Whilst a common understanding of the purpose of methodological approaches is to elucidate concepts, identify categories, or themes to understand certain phenomena, narrative portraiture brings the person to the fore and highlights that a portrayal of a sole story can be, not only a medium to understand a research phenomenon, but also a valuable research output in itself. Thus, in narrative portraiture the key 'finding' of a research project is the person's story. In communicating people's stories and providing the context in which these stories happen, the method involves the audience and recognises them as able to understand the phenomena under investigation, ask questions, and draw their own conclusions. In this way, readers/listeners are more active in the construction of knowledge and become witnesses to the existence of people whose lives are largely hidden from mainstream society.

In both of our research projects, meeting with participants and listening to their experiences and views made strong impressions on us. This made us look for a method that would allow us to acknowledge the research encounter when carrying out our analysis. We wanted to present findings that were contextualised in broader social spheres, while being able to evoke the impression of the people we had met. Some approaches to narrative analysis focus on short stories (Georgakopoulou, 2007) or on the conversational exchanges during the interview (Gee, 1986; Gee & Grosjean, 1984), but we aimed to see participants' narratives within the macro context in which these lives happen because we believe that life stories and identities are best interpreted holistically. As put by Catherine Riessman (1993), some people knit together a number of themes into coherent and extended accounts that make a categorisation process difficult and fragment what is an extended narrative. This narrative approach allowed us to map our data and visualise places where narrations addressed the intertwinement of individual and macro-social aspects.

Narrative portraits as an evocative method that builds a bridge between research and audiences

Depending on their data, researchers will be able to develop different kinds of portraits. In projects where the role of the researcher is more in the foreground, researchers might want to consider writing themselves into the story. Narrative portraits give space to researchers to include their own experiences and this might aid a more transparent reflection of the research process. By bringing their own reflections and experiences of the research process into the story, the role of the researcher is positioned and contextualised. We believe that this might lead to a more transparent account by making the situational conditions of the research process visible (that is, by explaining what it was like to be the researcher). Furthermore, the voice of the researcher can build a bridge between the reader and the participants' experiences as it can be used to offer reflections and pose questions. Similarly, because the developed stories stay embedded in the concrete actions and experiences of people and offer a more vivid and sensory account (Stake, 1995), they draw the reader in and build a connection to the reader's own personal experiences as they get a sense of 'being there' (Vanwynsberghe & Khan, 2007).

Narrative portraiture to help structure and make sense of data

One of the dangers of qualitative research, particularly for novice researchers, is the amount of data that is collected and the danger that the researcher loses focus and gets lost (Miles & Huberman, 1994; Yin, 2014). Narrative portraiture will help researchers to structure their data and understand complexity and ambiguity within narratives, without losing context, nor losing sight of individual accounts and perspectives. Within interviews, participants might express mixed views that could be seen as contradictory thoughts or feelings. However, this apparent contradiction does not invalidate potentially useful data; contradictions are often associated with the complexity of people's experiences that cannot be 'cleansed' to reflect neat findings. Contradictions might reflect changes in circumstances within participants' lives. Narrative portraiture is able to emphasise processes as they occur over time and therefore is able to illustrate complexity and ambiguities.

Narrative portraiture has the flexibility to be used across different data sources such as interview transcripts, observations, field notes, and documents. Researchers who use case studies or ethnography might find that the approach helps them to integrate their data. There is little literature on how to analyse data from different data sources and triangulation is often conceptualised as adding to research validity on the basis that different methods are thought to verify the same result. However, within our narrative approach, triangulation is not understood as a means to test for one single event or outcome. Instead, using different data sources resembles the process of piecing together a puzzle (Maxwell, 2012). The codes that we identified in Table 1 can be used across data sources to help researchers illuminate different aspects of their data and to look at it from different angles. For example, interviews can be coded using all five questions within Table 1; documents might give the researcher information about when events took place and who was there; while observations and fieldnotes can bring in the perspective of the researcher to reflect on key-events and phenomena of interest.

Conclusion

Through narrative portraiture, we analysed and arranged the structure of the data for the sake of coherence and flow, but the content remained mostly entirely verbatim. We argue that when the participant's voice cannot be included or the portrait requires additional narration from the researcher, we are explicit about how our researcher's voice shapes/influences the narrative. This is a crucial move that aims to account for the 'epistemic privilege' (Pillow, 2015) that defines what counts as valid knowledge, especially when the research poses the risk of reproducing oppressive dynamics for participants who have been disadvantaged or have experienced oppression. In one of the examples

that we used in this article, the narratives of gay men were analysed through this method and the final product was presented in their own words. This act seems essential in cases where groups have been deprived of the right to speak for themselves, such as Lesbian, Gay, Bisexual, and Transgender (LGBT) people, whose lives have been medicalised, criminalised, debated, and treated as profane by medical, legal, academic, and religious authorities but little opportunity has been given for them to say what being LGBT means to them. Thus, by focusing the analytic work on presenting a more complete and evocative narrative in their own words, narrative portraiture aims to minimise the common pitfall in which papers display a quotation of what a participant said and then the researcher ‘explains’ with their (our) authorial voice what they meant. Similarly, the second example used in this article followed young people with severe intellectual disability on their transition from school to adult services. Since young people were mostly non-verbal, the example shows an indirect portrait through the narratives of those involved in making decisions for them; parents, social workers, teachers, adult service staff, health professionals, and local authority management. The absence of these young people’s voices highlights the power that researchers – and other ‘experts’ – have in the portrayal of participants’ realities and invokes researchers’ reflexivity in creating methodologies that make transparent the research process and are accountable for the ethics of representation.

In the case of two of the themes we dealt with in our research projects, we are aware that these aspects interweave with, and are therefore inseparable from, many other areas of participants’ lives. The narrative portraiture method allowed us to acknowledge and manage that complexity while simultaneously focus on the phenomenon under investigation. The narrative portraiture method as an analytical tool suggests that the emphasis on complex narratives is, not only comprehensive of the ways in which people experience their lives, but also reflects the experience of the research encounter and makes both participants’ and the researcher’s perceptions more visible. This reminds us as researchers that behind the research findings or outputs, there are people whose stories should be honoured.

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