

What Meaning does Raising a Child with Autism have for
Parents? A Qualitative Exploration

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Declaration

I declare that this thesis has been composed by myself, and that the work contained here within is all my own. This thesis, nor any part of it, has been submitted for any degree or professional qualification other than that specified.

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Abstract

Introduction: Children with autism experience difficulties in social interaction and communication which are often manifested behaviourally. The nature of these difficulties means that the task of parenting is often challenging. This study therefore aims to explore which aspects of raising a child with autism are most meaningful for parents. It will also investigate what, if any, are the positive aspects related to the experience of having a child with autism.

Method: A qualitative approach was used, with data collection and analysis being guided by the principles of Interpretative Phenomenological Analysis (Smith, 1995). Seven interviews were conducted which yielded approximately 10 hours of data. Interviews were recorded and transcribed to facilitate analysis of the narratives.

Results: The meaning of being the parent of a child with autism was conceptualised within four core themes of: autism as a journey, what it means to live with autism; negotiating the social world; and positive aspects of raising a child with autism. Three of these themes contained sub-themes which provided further insight into the participants' experiences. Being the parent of a child with autism was represented as a complex and dynamic process.

Discussion: The results of the research are discussed in the context of relevant literature. Previous findings regarding receiving a diagnosis of autism, coping, acceptance and adaptation are essentially supported by this

research. However, these results also acknowledged the significant role of social encounters in the participants' experiences and the positive aspects of raising a child with autism. The clinical implications of the findings are discussed. Suggestions for future research are also made in response to the current findings and potential imitations of the methodology are considered.

Conclusions: The findings from this research indicate that being the parent of a child with autism is characterised by many meaningful experiences, some of which are significant moments in the process of raising a child with autism. For example, the journey to, and receipt of, their child's diagnosis was identified as a particularly important event in the experiences of the participants. Furthermore, there are complex interactions between the different aspects of these experiences which reflect the ever-changing nature of the challenges of parenting a child with autism.

1 Introduction

1.1 Aim of the Current Research

The aim of this research is to explore what it means to parents to raise a child with autism. To date there has been little research in this area, with autism research tending to focus on establishing causality or explaining symptom presentation. By using a qualitative methodology, the current study will obtain extensive and detailed information that is directly relevant to the participating parents and hopefully, therefore, to other parents of children with autism. The results of this research will provide an important insight into the emotions, thoughts and behaviours inherent in these parents' experiences, which will inform current understanding of what it can mean for parents to live with an autistic child.

This introduction will provide a background to the current research by presenting an overview of autism¹ and its diagnostic criteria and summarising key psychological theories of autism. The literature related to parents' experiences will be reviewed before the rationale for the current research is outlined. Extensive literature searches were performed on-line via the NHS Scotland e-library using the PsycINFO (1985-2008), MEDLINE (1996-2008), AMED (1985-2008), EMBASE (1996-2008) and CINAHL (1982-2008) databases. The following key words were used to facilitate the search process: autism, autistic spectrum disorder, autistic, parenting, parents, qualitative, positive impact, experiences and pervasive developmental disorder.

¹ All uses of the word *autism* in this document refer to autism as defined in the ICD-10 diagnostic manual as *childhood autism*.

1.2 Parents' Experiences of Autism

I can't think of any aspect of daily living that hasn't been encroached upon by autism in some way, at some time. (Moore, 2005; pp. 224)

But this is just how life is, and I don't waste time or energy fretting about it. One good thing about having children like mine is that they don't leave you much spare time for gloomy ruminations. (Moore, 2005; pp.233)

Literature searching identified five journal articles specifically related to exploring the broader aspects of parents' experiences of having a child with autism (Fleischmann, 2004; Fong *et al.*, 1993; Hutton & Caron, 2005; Schall, 2000; Woodgate *et al.*, 2008). In addition, an unpublished dissertation was sourced which highlights the individuality of some parents' experiences, and suggests that although there may be similarities across parents' experiences, there may also be differences (Glass, 2001). Published personal accounts were valuable in providing background and orientation to the issues likely to be important in the lives of families of children with autism (Ariel & Naseef, 2006; Carter, 2004; Hughes, 2003; Moore, 2005). Parents of children with autism face many challenges that parents of children with other developmental disorders may not. This difference is largely due to the fact that autism is a disorder of social-relatedness and, as such, parent-child communication and attachment are disrupted more than in other developmental disabilities (Siegel, 1997). As a result, only literature pertaining to autism was included in the literature review. In addition to research directly exploring parents' experiences, three key areas of research relevant to the current study were identified: receiving a diagnosis of autism; stress and coping; and adaptation.

Moore (2005) presents a factual account of her life with two autistic sons, both of whom are very different, and talks frankly about the challenges that she and her sons face in simply getting through each day. Her story about her sons highlights the individuality of autism; as she says 'two very different boys, same diagnosis' (pp. 88). Hughes (2003) also provides a heart-warming and open account of his life with his son Walker, and the way that he, along with his wife and younger son, negotiate their way around Walker's autism. Both authors tell their story from the time they realised that their child was not developing as expected, through the difficult process of diagnosis, coping with difficult behaviours, regression and progress, schooling and support issues, and how they and their family changed and adapted to their children with autism. But above all, their stories reflect a deep love and acceptance of their child and their autism as a whole. Mr Hughes recounts a conversation with his son's support worker...

I think I get as much out of these walks as Walker does. He looks out at the lake or at the trees or snow and he seems to enjoy everything so much. It's like a...I don't know...like a privilege to be with him.

I looked at her, embarrassed to feel so thrilled. 'She gets it' I thought, 'Somebody else gets it'. (Hughes, 2003; pp.232)

Whilst towards the end of her book, Moore declares...

On good days, on very good days, autism is its own compensation.
(pp. 241)

1.3 What is Autism?

Autism is one of several related developmental disorders which are collectively referred to as autism spectrum disorders². It was recently estimated that there are approximately 7714 children with autism spectrum disorders in Scotland (PHIS, 2001). However, due to the difficulty in accurately diagnosing autism spectrum disorders it is difficult to determine what proportion of these children have autism. It is known that autism is more common in males, at a ratio of 4:1 (SIGN, 2007). Whilst there has been a great deal of research into autism, to date this has largely centred on trying to understand the aetiology of the disorder, and on finding explanations for the nature of the deficits which define it. A report from the Medical Research Council, commissioned by the Department of Health, recently outlined the current state of scientific knowledge about the epidemiology and causes of autism (MRC, 2001). It is now well established that autism has a genetic component, although the mechanism by which this operates is not yet understood. However, it is suspected that several genes may act together to confer susceptibility (MRC, 2001). Nonetheless, it is possible that there may be a range of causes for autism, and certainly the role of environmental factors in its aetiology currently remains unclear.

1.4 Diagnostic Criteria for Autism

In the absence of any biological markers for diagnosing autism, the diagnostic criteria focus on the identification of a number of behavioural symptoms which are manifestations of qualitative impairments in social, communicative and imaginative development (MRC, 2001). The term 'triad of impairment' was coined to describe these core areas of impairment (Wing

² The term *autism spectrum disorders* is used as an umbrella term to refer to autism and all of its related disorders, including Asperger's syndrome and pervasive developmental disorder.

& Gould, 1979). There is a great range in the expression of autism in individuals such that, although there are likely to be commonalities to the symptoms displayed across individuals as a result of the underlying impairments, the impact of these symptoms on the individual and the meaning for their families cannot be assumed to be the same. In addition to the behavioural symptoms of autism, intellectual disability may also be evident, but again this varies across individuals such that some children with autism may have profound intellectual impairment whilst others are of 'normal' intellectual ability.

The diagnostic criteria for childhood autism, as documented in the International Classification of Diseases Manual-10th edition³ (ICD-10; WHO, 1990), are shown in Table 1. Guidelines for the assessment and treatment of autism spectrum disorders in Scotland were published last year (SIGN, 2007). They recommend that diagnosis of autism is only made following a specialist assessment comprised of developmental history taking, clinical observation and assessment, and obtaining systemic contextual and functional information. It is also suggested that professionals consider the use of ASD-specific observational instruments, such as the ADOS-G (Lord *et al.*, 2000), as a means of improving the reliability of diagnosis.

³ As this research is based within Europe, the ICD-10 criteria are used rather than those of the American DSM-IV.

- A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:
- (1) receptive or expressive language as used in social communication;
 - (2) the development of selective social attachments or of reciprocal social interaction;
 - (3) functional or symbolic play.
- B. A total of at least 6 symptoms from (1), (2) and (3) must be present, with at least two from (1) and one from each of (2) and (3):
- (1) Qualitative impairments in social interaction are manifest in at least two of the following areas:
 - (a) failure to adequately use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
 - (b) failure to develop (in a manner appropriate to mental age and, despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
 - (c) lack of socio-emotional reciprocity as shown by impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional and communicative behaviours;
 - (d) lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g. a lack of showing, bringing or pointing out to other people objects of interest to the individual).
 - (2) Qualitative abnormalities in communication are manifest in at least one of the following areas:
 - (a) a delay in, or total lack of, development of spoken language that is *not* accompanied by an attempt to compensate through the use of gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);
 - (b) relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present), in which there is reciprocal responsiveness to the communications of the other person;
 - (c) stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
 - (d) lack of varied spontaneous make-believe or (when young) social imitative play.
 - (3) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities are manifest in at least one of the following areas:
 - (a) an encompassing preoccupation with one or more stereotyped, restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their specific content or focus;
 - (b) apparently compulsive adherence to specific, non-functional routines or rituals;
 - (c) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements;
 - (d) preoccupations with part-objects or non-functional elements of play materials (such as their odour, texture, or the noise or vibration that they generate).
- C. The clinical picture is not attributable to the other varieties of pervasive developmental disorders: specific developmental disorder of receptive language with secondary socio-emotional problems; reactive attachment disorder or disinhibited attachment disorder; mental retardation with some associated emotional or behavioural disorder; schizophrenia of unusually early onset; and Rett's syndrome.

Table 1. ICD-10 Diagnostic Criteria for F84.0 Childhood Autism (WHO, 1990)

1.5 Psychological Theories of Autism

Historically, psychological research aiming to explain the cognitive deficits characteristic of autism has been dominated by three key theories: The Theory of Mind (ToM) Deficit, Executive Dysfunction and the Weak Central Coherence account (Rajendran & Mitchell, 2007). More recently, some support has emerged for the adoption of a multiple-deficit approach. A detailed discussion of this area is beyond the scope of this report. However, the key aspects of the three main psychological theories will now be considered.

1.5.1 *Theory of Mind Deficit*

This theory essentially proposes that individuals with autism lack ‘the ability to attribute mental states to oneself and others, and to make sense of and predict behaviour on the basis of mental states’ (Baron-Cohen, 1999). Theory of mind ability has most commonly been assessed using first-order tests of false belief (i.e. I think he thinks). However, while some research in this area has appeared to provide significant support for a ToM deficit (e.g., Baron-Cohen *et al.*, 1985), other researchers (e.g., Happé, 1994) have highlighted that these findings fail to support a ToM deficit as universal across all children with autism. Using a second-order false belief test (i.e. I think he thinks she thinks), Baron-Cohen (1989) suggested that autistic individuals had a delay rather than a deficit in their ToM development. He found that none of the autistic children in his sample were able to complete a second-order test despite having a higher average verbal mental age than typically developing children and children with Down’s syndrome. However, this finding was challenged by Bowler (1992) who found that some individuals with an autistic profile were able to pass second-order tests.

Happé (1995) conducted a meta-analysis and found that the probability of passing false belief tasks was strongly predicted by verbal mental age, suggesting that higher-functioning autistic individuals were likely to perform at ceiling. Advanced ToM tests were consequently developed for this population. Baron-Cohen *et al.* (1999) have since proposed that passing first and second-order false belief tests should be regarded as a step towards acquiring a theory of mind, not an end point. Thus, there is an implicit suggestion that advanced ToM tests require 'more' of an amount of a ToM, which is distinct from the original concept of theory of mind as something that is either absent or present (Rajendran & Mitchell, 2007). Advanced theory of mind tests have been criticised for being an apparent post hoc response to try and explain research data that does not fit with the original ToM deficit hypothesis (Rajendran & Mitchell, 2007). The same authors have also highlighted that advanced tests are not based around a test of the causal relationship between informational access and the consequent state of belief which, it has been suggested, is essential for identifying a representational theory of mind.

As the theory has developed so there has been some debate as to what theory of mind actually is. Most recently, Klin *et al.* (2003) re-conceptualised theory of mind as the Enactive Mind hypothesis. They argue that, from birth, the autistic mind is not attuned to the social world, as evidenced by differences in gaze and gaze-following patterns of autistic compared to 'neurotypical' infants, with the latter group appearing constantly prepared to find and interpret social meaning, even in non-living entities. This stemmed from the results of a Social Attribution task, which found that typically developing individuals would look for social meaning even in the relations between

geometrical shapes while individuals with autism would describe the relations in terms their physical properties (Klin, 2000).

In summary, despite the sometimes conflicting findings in this area, it seems probable that many individuals with autism have difficulties understanding both their own mind, and the mind of others. However, as yet there is still no consensus regarding the definition and theoretical underpinning of theory of mind (Rajendran & Mitchell, 2007).

1.5.2 Executive Dysfunction Theory

Executive functions (EF) are high-level skills such as: shifting attention, generating goal-directed behaviour, strategic problem-solving and inhibiting impulses. The Executive Dysfunction theory of autism was first proposed when researchers observed that some symptoms of autism were similar to those related to specific brain injury, but could not be easily explained by the theory of mind hypothesis (Rajendran & Mitchell, 2007). However, research attempting to differentiate disorders based on performance on EF tasks has yielded mixed and inconsistent results, which has raised questions about the universality of EF deficits in autism (Rajendran & Mitchell, 2007). A review of EF research by Hill (2004a, 2004b) suggested that evidence for a unique deficit in a particular EF in autism was unlikely. However, the author went on to suggest that it was still possible autism may be distinguishable from other neurodevelopmental disorders by a distinct EF profile. One of the key challenges for research in this area is being able design studies and tests that measure isolated aspects of EF (Rajendran & Mitchell, 2007). It has long been recognised that, while many EF tests purport to assess a specific function, they inadvertently tap into additional EF functions. Rajendran & Mitchell, (2007) also highlight that EF research in autism, as well as producing

inconsistent findings, has also suffered from some failures to replicate results even when identical methodologies and tasks are used. Rajendran & Mitchell, (2007) conclude by saying:

‘It seems that the EF hypothesis can explain many of the features of autism. However, its limitations are that not all individuals with autism show executive problems and those who do may have differing profiles of EF. Moreover, executive difficulties are not unique to autism and are seen in other disorders. A further issue is that some researchers have argued that executive abilities may be related to theory of mind. Others have countered this argument by saying that executive abilities are needed for theory of mind.’ (pp. 235).

Frye *et al.* (1995) and Zelazo and Frye (1997) have proposed Cognitive Complexity and Control theory (CCC) as an alternative approach to understanding EF and theory of mind in autism. CCC theory suggests that EF is related to theory of mind because both theory of mind and tasks of executive ability involve the use of higher order rules. It has been argued that the CCC framework is useful for understanding developmental disorders for three reasons: (1) it acknowledges the potential influence of intellectual impairment on other aspects of autism, and how this interaction might lead to the results seen in EF and theory of mind studies; (2) the theory allows researchers to determine the uniqueness of different disorders; and (3) CCC allows the comparison of performance on different tasks from different domains and therefore provides a test of specificity and uniqueness.

To summarise, the strength of the executive dysfunction theory lies in the fact that it can account for many of the non-social aspects of autism, and

indeed, is the only theory which recognises the cognitive and motor characteristics of autism. However, the theory has come under criticism regarding issues of specificity, uniqueness and universality (Rajendran & Mitchell, 2007).

1.5.3 Central Coherence Theory

One of the key strengths of Weak Central Coherence theory (WCC; Frith 1989, 2003; Frith & Happé, 1994; Happé, 1999) is that it can explain both non-social (e.g. attention to detail) and social characteristics of autism. The theory essentially proposes that, while typically developing individuals process information by extracting an overall meaning, individuals with autism lack this drive for coherence and thus process things in a detail-focused or piecemeal way (Rajendran & Mitchell, 2007). One positive feature of WCC theory is that it can be used to explain higher level conceptual abilities such as language. López and Leekham (2003) proposed that ability to detect WCC in autistic individuals was dependant on whether the task used was verbal and/or visual. The authors found no evidence for WCC using a visual task and consequently argued that WCC in autism is specific to complex verbal stimuli, particularly sentences that rely on context to disambiguate word meaning, and thus not a general deficit in autism. WCC theory has been subject to several interpretations which will be briefly considered.

The first of these relates to *visuospatial constructional coherence*. It has been suggested that the superior performance of autistic individuals on embedded figure and block design tasks is due to their lack of central coherence, and tendency to attend to the constituent parts of the tasks. However, research using visual illusions has produced inconsistent results with some studies showing autistic individuals as susceptible to illusions while other studies

indicate the opposite. It was subsequently suggested that this disparity might be related to higher-order processing in some way (e.g. Milne *et al.*, 2002; Mottron *et al.*, 2006), while the influence of question wording on task performance has also been raised (e.g. Brosnan *et al.* 2004).

The second interpretation of WCC theory is known as *reduced generalisation* (Plaisted, 2001). Plaisted proposes that autistic individuals show reduced processing of similarities between stimuli and situations while differences are processed relatively well. It is suggested that this can explain the superior performance of autistic individuals on block design and embedded figure tasks. According to the theory, the concepts of autistic individuals are narrower, sharper and have more clearly defined boundaries. Thus, this theory can potentially explain why people with autism often have difficulty generalising newly learned behaviour to a novel environment Rajendran & Mitchell (2007).

A third alternative account of WCC is *hierarchization* (Mottron & Burack, 2001; Mottron *et al.*, 2006), which stemmed from the finding that individuals with autism process hierarchical stimuli differently, in a way that cannot be easily accounted for by WCC theory. Several studies have endeavoured to investigate this with varying results. At present, most evidence indicates that autistic individuals experience unique interference from local to global processing of information (Rajendran & Mitchell, 2007). However, Mann and Walker (2003), incorporating the role of attention, argued that individuals with autism do not necessarily lack the ability to integrate local information to derive global meaning, but rather that it is difficult for them to do this when their attention has to be broadened.

Rajendran & Mitchell (2007) conclude that, as it stands, WCC has been redefined as superior local processing rather than a global processing deficit. Also, rather than being considered a deficit, WCC is now regarded as a cognitive style (Happé, 1999), albeit one which is biased towards attention to detail. Nonetheless, it is suggested that with effort autistic individuals may be able to extract the overall meaning of situations. Finally, WCC theory no longer seeks to explain all aspects of autism, but rather is seen as one aspect of cognition in autism (Happé & Frith, 2006).

1.5.4 Multiple Deficit Accounts

Multiple-deficit accounts (e.g. Baron-Cohen & Swettenham, 1997) propose that autism is a complex of cognitive disorders: impaired theory of mind, WCC and executive dysfunction. It is suggested that individuals can be affected differently in these three, possibly independent, domains. Some evidence for this was put forward by Pellicano *et al.* (2006) who reported that when age, verbal and non-verbal ability were removed, the theory of mind, EF and CC domains appeared to be unrelated to one another. Multiple-deficit accounts do not assume any hierarchical association between different cognitive characteristics (Rajendran & Mitchell (2007)). These accounts also have the potential to more adequately explain the heterogeneity of symptom expression across autistic individuals.

1.5.5 Summary

Each of the three key theories seems to have the potential to explain different aspects of the cognitive deficits seen in autism, and it is possible to see how this explanatory power might increase if they could be integrated. Ideally any theory of autism would need to be able to integrate the socio-linguistic, perceptual, sensorimotor and disordered movement aspects of the condition,

whilst also being applicable to individuals who had severe learning disabilities as well as those who are high-functioning (Rajendran & Mitchell (2007)). However, this seems a difficult task to achieve and it may be that multiple-deficit accounts are the only ones which can adequately cover the diversity of autism (Rajendran & Mitchell (2007)).

The diagnostic criteria for autism and what they mean in terms of everyday symptom presentation will now be discussed in more detail.

1.6 Further Consideration of the Diagnostic Criteria

In order to provide additional context for this research it is important to think about what the diagnostic criteria mean in relation to everyday functioning and how these impairments might present. Therefore, the three core symptom areas will now be discussed in more detail. It is important to be mindful that autism is a very individual experience and, while there will be commonalities in the core symptoms, the way in which these manifest may vary greatly. Similarly, whilst there will be some similarities in parents' experiences of having a child with autism, the meaning they attach to these experiences is likely to differ.

1.6.1 Social Interaction

By definition, all children with autism will show evidence of impairment in their social skills; however, these can vary greatly in their nature. Wing and Gould (1979) proposed that children with autism could be categorised according to three main types of impairment in social interaction:

- *Aloof*. This term is used to describe children who seem at their happiest when left alone. Eye gaze is actively avoided and these children often dislike physical contact. As infants, these children

show no distress at separation from their parents. Indeed, parents describe them as being 'in a world of their own' (Howlin, 1998).

- *Passive.* These children will not seek out social contact but, unlike aloof children, they do not actively avoid it either (Howlin, 1998).
- *Active but odd.* This group of children most usually includes those who are more intellectually and cognitively able. They have a tendency to talk *at* people, and show no awareness of social barriers. These children may have a particular obsession that they will endeavour to involve others in (Howlin, 1998).

It is important to note that these categories are by no means definitive. The social skills of children with autism often change as they mature; so, for example, an initially aloof child may later be considered to be active but odd.

1.6.2 Communication Skills

Lord and Rutter (1994) estimated that approximately half of all children with autism fail to develop functional speech, with many of these children also demonstrating little to no receptive language skills. Howlin (1998) notes that children with autism make no attempt to develop alternative communication methods, such as eye contact or use of gesture, as they age. Furthermore, when children with autism do learn to talk, their receptive language skills are generally poorer than their expressive language skills. In particular, understanding abstract concepts is difficult for children with autism, and their interpretation of spoken language tends to be literal. Notably, the most significant feature of language impairment in autism is the lack of communication in a social context.

Language impairment in autism not only impacts on ability to communicate and interact in the social world, but also inherently manifests in an inability to develop normal, imaginative patterns of play. Play behaviour in children with autism tends to be stereotyped, repetitive and solitary, which in itself further undermines the development of social communication with peers. In fact, on occasions when children with autism are encouraged to play with their peers, they often dominate the play (Howlin, 1998).

1.6.3 Repetitive and Stereotyped Behaviours

Most children with autism will usually display some form of repetitive or stereotyped behaviour, although the nature of this will be dependent upon intellectual ability. It is not uncommon for these behaviours to become so severe that they are extremely disruptive to family life. Whilst children of lower cognitive ability may engage in simple stereotyped behaviours, such as playing with rubber bands, a child of higher ability may be more particular about playing only with rubber bands of a certain size. Children may also become very rigid about their acceptance of certain things, for example, certain colours of food. It is also common for some children to develop attachments to and make collections of particular objects, and whilst these objects themselves may not be unusual, the intensity of their interest and the size of the collection may be. Alternatively, some children have specific preoccupations or interests. Finally, frequently children will have a need for routine that makes them resistant to change, and indeed disruption to these routines can result in intense distress. By definition, this distress affects not only the child, but also those around them.

It seems reasonable to conclude from this discussion that being the parent of a child with autism is likely to present a number of challenges, to the parent

and to the wider family and its context. Furthermore, as parents become increasingly more aware of the full impact and implications of their child's autism, these challenges are likely to be amplified (Fleischmann, 2004). Before going on to reflect on some of these challenges by reviewing the literature on the broader aspects of parents' experiences of raising a child with autism, the more specific area of receiving the diagnosis will be reviewed.

1.7 What does Receiving a Diagnosis of Autism Mean?

Research into how families respond to receiving their child's diagnosis of autism has shown that receiving a diagnosis is a complex process that frequently begins when parents recognise that there is something 'different' about their child and their behavioural development (Hutton & Carron, 2005; Midence & O'Neill, 1999; Osborne & Reed, 2008). Osborne *et al.* (2008) recently reported results suggesting that the time at which parents first notice a problem can be predicted by the severity of their child's autism. Furthermore, they found that the age at which a child was diagnosed could be predicted by the age at which problems were first noticed by the parents. For some parents, the recognition of there being something 'different' about their child has been followed by confusion as the journey to official diagnosis begins and different explanations for their child's differences are explored. Hence, some parents have reported finding the diagnostic process complicated and lengthy (Hutton & Carron, 2005; Osborne & Reed, 2008). Immediate reactions to diagnosis, as described by parents, tend to be characterised by mixed emotions, predominantly fear and shock, often accompanied by feelings of isolation and uncertainty and, in some cases, guilt or anger. However, parents have also described diagnosis being accompanied by a sense of relief at knowing what was wrong and now

knowing what they were dealing with (Midence & O'Neill, 1999; Osborne & Reed, 2008). Some parents have also reported diagnosis as a relief because they no longer felt guilty or blamed for their child being different, and because they now had a sense of direction (Nissenbaum *et al.*, 2002). For many parents therefore, diagnosis is a turning point as it acknowledges their need to access support. This subsequently helps parents to move forward to acceptance of the autism and adaptation to a new reality of what life is going to be like. It seems that for many parents, diagnosis is not a static and isolated event but a complex and dynamic process.

Some parents have likened receiving the diagnosis to a process of grieving (Carter, 2004; Nissenbaum *et al.*, 2002). However, because developmental disabilities are not final in the way death is, although the onset of the grief may be similar to bereavement, over time there may be less chance of a complete resolution (Siegel, 1997). Indeed Glass (2001) distinguished between grief and sadness in relation to raising a child with autism for the parents in his study. He proposed that grief related to the parents' lifelong perception of their child's life, and issues such as who would care for their child when they died. Meanwhile, profound sadness was seen as a product of the daily occurrences which served to remind the family of the consequences of their child's autism. Siegel (1997) presented a theoretical model for the stages of healthy versus complicated coping with the diagnosis of autism. It is similar to existing grief models and suggests that during healthy coping, parents will go through stages of outcry, denial, intrusion and working through, before finally achieving a state of stasis. At this stage, Siegel suggests that parents reach an acceptance of the autism as part of their child and, whilst some residual sadness may remain, the parents are able to accept the reality of their child's future. An examination of parents'

narratives has indicated that parents may indeed go through a staged process of adapting to their child's autism following the diagnostic process (Fleischman, 2004). Prior to diagnosis, some of the parents in Fleischman's study described feelings of anxiety and powerlessness about their child's behaviour. Once these parents had dealt with their emotions about the diagnosis they often reported that they began to educate themselves about autism and available interventions. Transition and acceptance of the autism was said to be rapid in some cases and, over time, a more positive stance was usually adopted towards the autism. As the data in Fleischman's study was obtained from online narratives and reliability of authorship was not established, the author sought verification from other parents of children with autism, who indicated that the narratives represented the reality of their experiences.

Importantly, there has also been some research that has explored parents' experiences of the content of the diagnostic process (e.g. Nissenbaum *et al.*, 2002; Osborne & Reed, 2008). Osborne and Reed (2008) reported that when their participants reflected on something positive about the diagnostic experience, this usually concerned the relief that they felt in having their suspicions confirmed that there was something wrong with their child. In many cases, parents have described feeling left alone without appropriate sources of information or support following the diagnosis (Hutton & Carron, 2005; Whitaker, 2002). However, Osborne and Reed (2008) found some differences between the parents in their focus group study regarding when the parents would have preferred to receive information about ASD. They reported that whilst more than two thirds of the parents of pre-school and primary-aged children expressed a need for information immediately after diagnosis, half of the parents of secondary school-aged children indicated

that they would have preferred to receive information as part of a phased follow-up. Parents have also recalled aspects of their experience, such as body language, the language used to share the diagnosis, and whether the professional was willing or able to discuss prognosis, as being influential in their experience of the diagnostic process. As Nissenbaum *et al.* (2002) note 'each family is unique in their needs and perceptions of autism. It is essential that professionals obtain an understanding of these needs and perceptions...' (pp. 38). It seems reasonable to conclude that it is important for parents that professionals endeavour to tailor the diagnostic experience to their particular family. Indeed, this is the message that is given to professionals who are giving any diagnosis, and is generally recognised to be good practice.

Receiving a diagnosis of autism for their child has been described by some parents as a significant and stressful life event. The experience may be made more difficult due to the uncertainty that stems from the fact that children with autism differ widely, and their lives have a variety of outcomes. In addition, for some parents, diagnosis may bring the loss of hope and expectations for the child they thought they had, and a dawning awareness of the limits that the autism will place on their child's life. Parents often perceive that they are likely to have to remain more involved in caring for their child even as they move into adulthood, which is different from the typical life cycle of parents and children. Frequently this is accompanied by a realisation that it is probable that this care will need to continue to be provided beyond their lifetime. These are overwhelming prospects that cannot be fully appreciated by anyone who has not been in this situation. The relevance of diagnosis to the ongoing experiences of parents of children with autism is clear. Diagnosis is a significant and meaningful moment in their lives, which is remembered long after the actual event. This chapter

will now go on to discuss the longer-term impact of raising a child with autism.

1.8 Parental Stress and Coping with Autism

‘Many traits of autism exacerbate the most challenging aspects of parenting any child’ (Siegel, 1997; pp. 753) and it is important therefore, to acknowledge the potential impact that parental stress may have on the management of a child’s autism (Lecavalier *et al.*, 2006). The vast hidden costs to carers’ health in regard to the stress and sleeplessness that are frequently experienced by families caring for a child with autism have now been acknowledged at a parliamentary level (Loynes, 2001). Mothers, in particular, are considered to be at a higher risk of presenting with mental health problems and it is thought that stress is a key factor in this (Piven and Palmer, 1999). Furthermore, it has been noted that these costs to carers’ health can often have a far-reaching impact on relationships. Anecdotally it is widely accepted that families with a child with autism are more vulnerable to marital breakdown (Loynes, 2001). Additionally, research into families under stress has shown that a link exists between relationship breakdown and poor physical and mental health, which may have further implications for the quality of family relationships. In her conclusions Loynes (2001) recommended that families of children with autism be provided with more emotional and practical support, and that health professionals be more aware of the strains that caring for a child with autism can have on relationships. ‘Stress and family adaptation appear to vary considerably as the child develops through infancy, childhood, adolescence and into adulthood. It is unlikely that parenting stress changes linearly as the child ages, but parents’ experiences of stress changes over time’ (Hastings *et al.*, 2005a; pp. 379).

It is important to highlight that it is not necessarily the child with autism who acts as the source of stress in the family. Rather there may be external stressors, such as lack of appropriate services, or insufficient special education provision (Sivberg, 2002). In addition, some parents have identified indirect effects of their child's autism, such as the loss of free time for relaxing, the impact on family activities and spontaneity, stress on the marriage, safety concerns, and a fear of their child hurting themselves or others, as contributing to their stress (Hutton & Carron, 2005). Nonetheless, some authors (e.g. Hastings & Brown, 2002) have reported that behaviour problems are the most significant predictors of parental stress in children with disabilities. It is known from the very nature of the symptoms of autism that it is common for children to exhibit behaviours that are difficult to understand and manage. Indeed, a recent study reported that behaviour problems were more associated with stress than any of the other child/caregiver characteristics measured, with conduct problems and lack of pro-social behaviours being the most strongly associated with increased stress in caregivers (Lecavalier *et al.*, 2006). This was recently supported by Osborne and Reed (2008), who reported that not only did autistic severity contribute independently to levels of parenting stress, but so did the child's age at diagnosis, with younger age at diagnosis being equated with greater levels of current parenting stress. Duarte *et al.* (2005) also reported that having a child with autism is the main factor in mothers presenting with stress. However, they identified some maternal personality characteristics which contributed to increased stress levels in the mothers in their sample. These included: the mother demonstrating little expression of emotion, low interest in people, being an older mother, or having a younger child. However, some unanswered questions remain. For example, is low expression of emotion a cause or a consequence of stress? Nonetheless, it

appears that for some mothers the experience of having a child with autism is relatively more stressful than for others.

1.8.1 The Role of Social Support

When considering stress in any context it is important to think about the role of social support. In some families, mothers have been shown to suffer higher levels of anxiety and depression than fathers of children with autism (e.g. Gray & Holden, 1992). The reasons for this are not clear, but it seems reasonable to speculate that it is due to mothers tending to assume primary responsibility for the day-to-day care of their child. As a result they are less likely to be in full-time employment, thereby not benefiting from the social support that work colleagues often provide (Sharpley & Bitsika, 1997). Indeed, Sivberg (2002) found that parents of children with autism scored low on a measure of social support, although he suggests that this may partially reflect that their social networks have deteriorated over time. However, it has been shown that the degree to which social support is perceived to be available may be a more important determinant of maternal stress levels than the actual level of support provided (Bristol, 1987). Sharpley and Bitsika (1997) reported that the parents in their study achieved consistently lower scores on measures of depression, anxiety and daily stress when they had support with child care from a family member. Interestingly, parental wellbeing was significantly influenced by the level of understanding that parents felt the family member had of the child's problems. Therefore, it seems that the benefits of social support are not necessarily just about the fact that it is there. Rather, parents' perceptions regarding different aspects of social support play a key role in the level of benefit that they derive from it. In some instances, access to social support may be affected by the wider family being experienced as unaccepting of the autism (Hutton & Carron,

2005). Given the potentially valuable supportive role of these relatives, this may have further implications for the experiences of parents trying to care for their child with autism.

1.8.2 Coping Strategies

Parents have been found to use a variety of coping strategies in addition to social support, including: use of service agencies, social withdrawal, religion, normalisation, individualism and activism. However, no one coping strategy has been identified as more successful than another, and families have reported varying the strategies they used according to the particular problem. That said, use of service agencies and family support seemed to be the most successful strategy for a substantial number of parents (Gray, 1994; Gray, 2006). Parents have also described an important coping strategy as planning ahead, anticipating difficulties that may arise in a given situation, and devising a response that could be implemented if necessary. Another common coping strategy was to take life one day at a time and deal with problems as they arose. Parents felt that it was not realistic to plan for every eventuality because life was too full of unexpected events (Gray, 2003; Hutton & Carron, 2005).

Previous research has indicated that there may be a negative relationship between level of strain on the family system and level of coping (Sivberg, 2002), with the suggestion that it is important for parents of children with autism to identify and employ a range of adaptive coping strategies. However, Higgins *et al.* (2005) reported results which found that coping strategies did not appear to be related to marital or family adjustment. Nonetheless, the participants in Higgins' *et al.* (2005) study reported lower levels of marital happiness, family adaptability and family cohesion than

normative data. Sivberg (2002) reported that, relative to families of normally developing children, parents of children with autism scored higher on use of the avoidant coping behaviours of distance and escape. However, although these are generally considered to be maladaptive, these strategies can be functional in certain situations. For example, distancing oneself from the autism following diagnosis may act as a protective mechanism in the early stages of adapting to the reality of the situation. In contrast, Higgins *et al.* (2005) identified self-esteem, optimism and spousal support as the three main coping strategies employed by the primary caregivers in their study. Other parents have described that they often coped by separating themselves to spend time with their developmentally normal children as well as their child with autism, although they acknowledged that this tended to have a negative impact on the family as a coherent unit. It has also been reported that cognitive coping strategies such as adjusted expectations, living in the present and appreciation of 'little things' are effective for some parents (Glass, 2001).

Gray (2006) sought to investigate how families' use of coping strategies changed over time, and found that parents followed up from his 1994 study cited using far fewer coping strategies 12 years later. This may be a positive reflection of an improvement in their child's symptoms, and consequently a reduced degree of emotional distress for the parents because their child was easier to live with. Reduced use of coping strategies may also reflect the increased age of their child and the parents being relatively further forward in the adaptation process than they were at the time of the previous study. Gray (2006) found that parents' use of treatment services had declined as a coping strategy, but again this may be a reflection of their child's increased age, and possibly also reduced availability of services for the parents in his

sample. Over time the parents in Gray's study reported increased use of emotion-focused coping strategies, which included the adoption of more philosophical attitudes and emotional responses to difficulties.

1.8.3 Gender Differences in Stress and Coping

Another area worthy of consideration is the differential experiences of stress and coping within the family unit of the child who has autism. To date, most research has focused on mothers, with some acknowledgement of fathers. Even when both parents have been included in a research study, for the most part they have been considered independently of one another. However, the reality that 'family members do not all experience similar effects as a result of being a relative of a child with autism' (pp. 635), and the fact that research has tended to focus on the autistic child as the source of stress in the family has recently been recognised (Hastings *et al.*, 2005b). It has therefore been proposed that a systemic conceptualisation might be more appropriate as this would recognise the probability that family members all affect one another. Gray (2003) reported that the most striking difference between parents in his study was the perceived personal impact of the child's autism. With regard to mothers, he found that they were more likely to cite an effect of their child's autism on their emotional wellbeing. Fathers generally reported that their child's autism affected them indirectly, via the stress experienced by their partners. Fathers were therefore most likely to see themselves as a source of support for their partners in times of increased stress.

Further investigation of gender differences has found that while mothers may report more difficulties than fathers, there was no difference between parents in reported levels of stress (Hastings *et al.*, 2005b). For mothers, a

strong positive relationship between their stress and their child's behaviour problems was found, with no apparent effect of adaptive behaviour or severity of autism symptoms on stress. There was also some effect of their partner's depression. However, in the case of fathers, the relationship with the child's characteristics did not hold, and paternal stress was found to be positively predicted only by their partner's depression. It seems possible then that there may be some interaction between parents' mental health states. However, the mechanisms by which these influences might work require further exploration. With regard to the finding that mothers are more affected by their child's behaviour problems, one potential explanation put forward by Hastings *et al.* (2005b) is simply that mothers are typically more involved in the care of their child with autism. A second explanation suggested is that the difference might be due to fathers employing different coping strategies to manage their child's difficult behaviour, which are more adaptive in reducing their stress. One study has reported that mothers tended to describe more use of practical coping strategies such as engaging their child in a therapeutic regime, and keeping the child with autism separated from their siblings. In contrast, fathers more often described keeping their child busy when they were at home and going to work as their most common coping strategies (Gray, 2003). Going to work was considered important by fathers as it created a role for them that was separate from the family's domestic life and, in some cases, fathers acknowledged that work allowed them to reduce the amount of time they spent with their autistic child.

In terms of emotional coping strategies, Hastings *et al.*, (2005a) reported that fathers were more likely to describe trying to suppress their feelings, whilst mothers were more likely to report that they vented their emotions,

expressed a greater variety of emotions, and used social support as a means of dealing with these emotions. It was found that mothers used both active avoidance and problem-focused coping strategies more frequently than fathers, with the former being related to increased levels of stress and mental health problems. Hastings *et al.*, (2005a) proposed that a disruption in marital support due to depression in one partner may account for the finding that maternal and paternal depression predicts the partner's stress. Fathers rarely cited any additional strategies to those already discussed.

In summary, it seems probable that mothers and fathers in families of children with autism utilise different coping strategies in accordance with the gender roles that they adopt. One could speculate that it appears to be the case that, in line with the general population, traditional gender roles are adopted in these families: mothers become the primary caregiver and, if they do work outside the home, it is on a part-time basis, whereas fathers take on the role of main breadwinner. Mothers are therefore spending more time with their autistic child and as a consequence they are likely to be required to adopt various coping strategies in order to effectively manage this. In contrast, fathers may have less time with their autistic child and so are perhaps not required to employ the same level of coping strategies. When interpreting the findings on stress and coping, it is important to consider whether mothers and fathers may also interpret their child's autism differently (Gray, 2003). Furthermore, an examination of the degree to which the experience of stress is affected by factors external to the family may further help to explain differences in the coping approaches used by mothers and fathers. It is somewhat difficult to draw firm conclusions from the research on coping due to the variation in measures used by studies in quantifying variables such as coping strategies and level of family strain.

These studies also drew on relatively small sample sizes and, with the exception of Gray (2006), have all been of cross-sectional design. This makes it difficult to make comparisons across the studies and, thus, to make any conclusive statements about what does and does not work in terms of coping effectively or otherwise with an autistic child.

Having considered the literature on parents' experiences of receiving a diagnosis of autism for their child and the literature on stress and coping with autism, the focus will now shift to reviewing the literature regarding adaptation and the broader aspects of being the parent of a child with autism.

1.9 Adaptation and the Experience of Raising a Child with Autism

Adaptation can be considered as being somewhat conceptually different to coping. Whilst coping can be regarded as being concerned with the more immediate strategies that families use to manage stress, adaptation refers to the longer-term adjustment and acceptance of a situation to which coping strategies contribute. By definition, adaptation is linked to the wider context of parents' experiences of their child's autism. These experiences influence how parents interpret and manage the autism and its symptoms as they accept the autism as part of their child and, consequently, as part of their lives. It therefore seems pertinent in this section to return to the literature on parents' experiences. There have been a number of models proposed to try and explain adaptation and two of these will now be considered in the context of autism: the ABCX model (Hill, 1958; McCubbin & Patterson, 1982) and cognitive adaptation theory (Taylor, 1983).

1.9.1 ABCX Model of Adaptation

The basic tenet of the ABCX model of adaptation, as put forward by Hill (1958), was that A (stressful event) interacts with B (family's crisis-meeting resources) and C (the family's perceptions of the stressful event) to produce X (the crisis). The main focus of the model is the interaction between the A, B and C (the pre-crisis) variables, their influence on X and, consequently, their role in accounting for the differing abilities of families to cope with the aftermath of stressful events or transitions. Hill proposes that the pre-crisis variables determine if a crisis will occur and, if so, what the extent of the crisis will be.

The ABCX model was later expanded to become the double ABCX model by including the key dimensions of family *post*-crisis behaviour that are involved in adaptation (McCubbin and Patterson, 1982). A, B and C still represent the same aspects of crisis-related behaviour but are now considered in terms of pre- and post-crisis in order to determine the extent of the crisis (X). Hence the model becomes $AaBbCc=X$. It has been argued that including the post-crisis variables gives us greater understanding of why it is that some families cope more effectively with hardship (Behr *et al.*, 1992). The central concept in the model is that, following a family crisis, family adaptation results from the family's efforts to reach a new level of balance. Therefore, adaptation refers to the new level of functioning that is achieved over time as part of the adjustment process, which ultimately serves to 'maintain family unity, to facilitate the wellbeing of family members and to enhance the family system' (Behr *et al.*, 1992).

Bristol (1987) applied the double ABCX model to investigate adaptation in 45 families of children with autism or a related communication disorder.

Bristol's model consisted of impairment⁴ severity, other family stresses (stresses indirectly caused by or unrelated to the child), family resources of cohesion and support, family definition of impairment, and adequacy of coping patterns. The findings indicated that mothers reported receiving less support from their husbands than vice versa, and this was particularly in relation to instrumental and emotional support. The overall study findings indicated that family adaptation was predicted by adequate social support and active coping patterns. Poorer adaptation was predicted by unwarranted maternal self-blame for the child's impairment, maternal definition of the impairment as a catastrophe, and other family stresses. Essentially, the findings indicated that parental resources and beliefs were more predictive of adaptation than the severity of the child's impairment.

1.9.2 Cognitive Adaptation Theory

Cognitive adaptation theory (Taylor, 1983) contends that people respond to personally threatening events through a process of adjustment that involves the resolution of three cognitive themes: search for meaning, perceiving mastery/control, and enhancing self-esteem. Taylor (1983) proposes that there are specific types of cognitions associated with each of these themes. Successful resolution of the themes is said to be dependent upon a person's ability to form and maintain a way of looking at a threatening event from a more positive perspective. Briefly, search for meaning involves an analysis of the event to try and determine cause and reason, followed by an evaluation of what meaning the event has in the context of the person's life. Perceiving mastery/control is comprised of cognitions relating to the person's beliefs about whether they have direct or indirect control over the course of

⁴ Bristol (1987) used the term *handicap* in her original article.

the event. Positive adjustment is associated with a balanced perception of direct and indirect control (Behr *et al.*, 1992). Finally, enhancing self-esteem is characterised by cognitive themes of downward and upward social comparisons, that is, comparing yourself to others perceived to be less and more fortunate respectively, in an attempt to learn how to cope more effectively. This stage of adaptation also involves efforts to construe positive meaning from the stressful event.

Both the double ABCX model and cognitive adaptation theory recognise family belief systems as one of the most important factors affecting adaptation. King *et al.* (2006) conducted a qualitative investigation into changes in the belief systems of families of children with autism and Down's syndrome. The study was carried out in the context of previous research, which indicated that with time and experience, parents of children with disabilities often regain a sense of control and meaning in their situation by recognising the positive contributions their child has made to their life. King (2006) highlights that, traditionally, research has focused on outcomes such as stress and depression, with little consideration of how children with autism or other disabilities can contribute positively to family life or the family's evolving life experience. Examination of data from three focus groups resulted in the identification of four key themes characterising the adaptation of the parents in the study. These, with their sub-themes listed in brackets, were:

- Initial reactions to being a parent to a child with a disability (life-changing experience, lost dreams);
- Adapting over time (examining beliefs, importance of hope and seeing possibilities ahead, gaining a sense of control and empowerment);

- Changes in world views and values (stronger values and broader world views, areas of personal growth, learning what is important in life); and
- Changes in priorities (giving up trying to 'fix' the child, refocusing on other family members).

These findings indicate that, for these parents, raising a child with a disability has been a life-changing experience that has prompted the families to examine and refine their beliefs. It was unclear from King's study what the relative proportions of participants who had children with autism or Down's syndrome were. Although it is likely that there will be similarities in the experiences of parents of children with both conditions, it would be interesting to explore how these findings relate specifically to parents of children with autism.

Whichever model of coping and adaptation is ascribed to, it is important to be mindful of the fact that there is great diversity among families, and no one reaction or sequence of reactions will be found in all parents of children with autism. In addition to predisposing characteristics that shape parental reactions, situational factors will also play an important role in determining parental responses to autism (Seligman & Darling, 2007).

1.9.3 The Holistic Experience of Autism

Recently, interviews with parents from sixteen families concerning their lived experience of having a child with autism revealed that these parents' experiences were characterised by a sense of 'living in a world of our own' (Woodgate *et al.*, 2008). The authors described this sense of 'living in a world of our own' as essentially reflecting a sense of the parents' isolation, which

was identified as stemming from: society's lack of understanding; missing a 'normal' way of life; feeling disconnected from the family; and the unsupportive 'system'. Woodgate *et al.* (2008) went on to describe three themes that emerged to support the overall essence of the parents' experiences of 'living in a world of our own' (sub-themes in brackets):

- Vigilant parenting (acting sooner rather than later, doing all you can, staying close to your gut feelings);
- Sustaining the self and family (working towards a healthy balance, cherishing different milestones, learning to let go); and
- Fighting all the way (becoming more direct, learning all they could, educating others).

These findings provide a valuable contribution to the literature aimed at understanding the lived experience of the parents of children with autism. The authors suggest that their findings are unique in that the parents' described their isolation being due to external sources rather than a consequence of their own actions. Additional identified research has reported on other differences in the experiences of parents. For example, Fong *et al.*, (1993) reported six themes that captured the essence of eight parents' experiences. These were: behavioural concerns; social and communication concerns; family-related concerns; education and related services; relationships with professionals; and independence and future concerns. In themselves, these themes seem to be fairly self-explanatory and further highlight the multi-faceted nature of these parents' experiences. Certainly the first two themes provide support for the research already discussed, which highlights the considerable stress that the symptoms of autism can cause. These findings were later supported by Schall (2000) who interviewed three sets of parents and sibling, not including the child with

autism. Using a narrative style to integrate her discussions with the three families, Schall (2000) identified four core themes that represented the experiences of these parents: (1) experience within the family; (2) the external experience loop; (3) the bridge out of the loop; and (4) hope. These themes were encapsulated within two summary categories of *experience within the family* and *external experience*.

External encounters related to having a child with autism are likely to be extremely important in contextualising and informing parents' experiences. A recent report from the National Autistic Society (NAS, 2007) reported on a comparison of public perceptions and service users' experiences of a lack of awareness and understanding of autism from the general public. Amongst the reported findings NAS noted that, whilst awareness of autism is high, there continues to be an apparent lack of understanding about what it really means to live with autism (NAS, 2007). Furthermore, it appeared that there is a lack of understanding and awareness about some of the key characteristics of autism. Approximately a quarter of the people interviewed mistakenly believed that autism affects children only, whilst more than half did not realise that there is no cure for the condition. The report also found that initial reactions to behaviours typically associated with autism are frequently negative, but just under two thirds of participants said that knowing that someone has autism would make a difference to the way they think. This latter point is noteworthy and suggests that some members of the public may be receptive to information educating them about the experiences associated with raising a child with autism.

1.10 Literature Review Summary

This literature review has considered the research into the experience of raising a child with autism. In addition, the literature on receiving a diagnosis, stress and coping, and adaptation was also reviewed to provide further context for the current research. It is clear from the literature base that parenting a child with autism is complex and, certainly in the early years, is characterised by grief and stress. Over time, most parents will identify coping strategies that work for them and, in turn, adapt to the experience of having a child with autism. Autism can have a profound impact not only on the diagnosed child, but also on immediate and extended family members, as well as on other systems external to the family, such as relationships with friends, education and health professionals and support organisations. The impact of autism is often felt not only in practical terms, but also behaviourally, emotionally and cognitively, thus families will tend to make sense of the autism and its impact in ways that are meaningful and adaptive for them. Families often identify positive aspects of their child's autism, which likely lessens the impact of the negative aspects and facilitates adaptation.

1.11 Rationale and Aims of Current Research

The current research aims to address the concerns raised by Loynes (2001) and the National Autistic Society (2007). Both of these reports recognise the impact on the family of raising a child with autism and, in doing so, highlight the distinct lack of research in this area. An extensive search of the existing literature confirmed this. Only a handful of research studies were identified that directly claimed they intended to explore parents' experiences. These studies were carried out in America and Canada, so there may be cultural aspects of their participants' experiences that need to be

taken into account. The related literature provided some further insight into the impact of having a child with autism, which was important for contextualising the literature on the broader aspects of parents' experiences. However, it is clear that there is a need for further research exploring the experience of raising a child with autism, and what this means for parents. In particular, only two studies (*Fong et al., 1993; Woodgate et al., 2008*) have given parents the opportunity to determine the focus of what is talked about, which perhaps limits understanding of the particular elements of the experience that are most significant and meaningful to them.

The overall objective of the current study, therefore, is to explore parents' experiences of raising a child with autism in Scotland, and what this means to them. In order to meet this objective the research aimed to explore the following areas:

- Which aspects of raising a child with autism are most meaningful for these parents?
- Does the experience of having a child with autism impact on the family system and social and work circumstances?
- What, if any, do these parents consider to be the positive aspects related to their experience of having a child with autism?

A qualitative methodology was chosen so that rich and detailed information directly relevant to the participating parents could be gathered. The results of this research provide important information regarding the emotions, thoughts and behaviours inherent in these parents' experiences, and will inform current understanding of what it can mean to live with autism. It is anticipated that the results of this research can then be used to inform clinical practice by educating professionals and acting as a resource for families who are adjusting to having a child with autism.

2 Methodology

The aim of this chapter is to clearly outline the procedures that guided data collection and analysis. An overview of the theoretical background is also provided and important ethical issues are considered. The characteristics of the participant sample are also provided in this chapter.

2.1 Study Design

A qualitative design was identified as the most appropriate to meet the research aim of exploring the meaning inherent in the experiences of parents raising a child with autism. Qualitative approaches considered were: narrative, grounded theory and phenomenology, which will each be briefly outlined. The narrative approach is concerned with the detailed chronological re-telling of the stories or life experiences, usually of one person or a small number of individuals, within a sense-making framework (Creswell, 2007). Narrative approaches are labour intensive in that they generally require information to be gathered over a considerable time period and from a number of sources (e.g. interview, diary, and observation). They also necessitate the collecting of contextual information for the story. Secondly, grounded theory was considered. The intent of grounded theory is to move beyond description in order to develop a theory that will account for a particular phenomenon (Creswell, 2007). Grounded theory requires data collection and analysis to run concurrently to facilitate theory development until theory saturation is reached. Grounded theory assumes that the literature review is done post-analysis so that the developing theory is not influenced by prior knowledge. The final approach considered was phenomenology. Phenomenological research aims to describe the

psychological meaning for several individuals of their lived experiences of a particular phenomenon identifying the aspects that a group of participants have in common (Creswell, 2007).

It was decided that a narrative approach was inappropriate for this research due to its focus on a very small participant numbers and the extensive time requirement for data collection and analysis. Equally, grounded theory was deemed unsuitable due to its goal of theory development, which does not fit with the research question. It was felt that the requirement to isolate oneself from the literature was impractical for the current research question. There was also considered to be a risk in terms of the potential time needed to achieve data saturation. Therefore, a phenomenological approach which is best suited to research where 'it is important to understand several individuals' shared experiences of a phenomenon' (Creswell, 2007; pp. 60), was deemed to be most appropriate to answer the research question. Within the phenomenological approach, the research was conducted using the theoretical framework of Interpretative Phenomenological Analysis (IPA; Smith, 1995), which is one type of phenomenology. IPA is discussed further below. Phenomenological approaches, in particular IPA, have become increasingly used over recent years in areas such as clinical and health psychology (e.g. Arroll & Senior, 2008; Moore *et al.*, 2008; Wallace *et al.*, 2007; Woodgate *et al.*, 2008), as researchers have become more interested in developing a greater understanding of peoples' lived experience of certain phenomena.

2.1.1 Interpretative Phenomenological Analysis

IPA is particularly suited to topics where there is a desire to understand how people perceive and understand significant events in their lives (Smith &

Eatough, 2007). However, even though IPA endeavours to explore participants' experiences from their own perspective, the approach recognises that this kind of exploration necessarily implicates the researcher's own view of the world, and may be influenced by the nature of the interaction between the researcher and participant (Willig, 2001). Hence IPA involves two levels of interpretation; the researcher is trying to achieve a balance between being empathic to the participant's experiences, while at the same time they are stepping back to take a more critical role, asking questions of the data to develop a deeper understanding of what is happening in the participant's account (Smith & Eatough, 2007). IPA recognises that the quality and texture of individual experience is never directly accessible to the researcher and, as such, the analysis developed by the researcher is always an interpretation of the participant's experiences (Willig, 2001).

The use of semi-structured interviews was selected as the most suitable data collection method as it would allow for the gathering of information of sufficient depth and quality to provide a detailed picture of participants' experiences. It was anticipated that this would be pertinent for the parents in this study, given the significance that the experience of raising a child with autism is likely to hold for people. As the research question is focused on gaining an understanding of a specific type of experience, a purposive sampling strategy was identified as the most effective way of recruiting participants.

2.2 Ethical Considerations

2.2.1 Ethical Approval

Ethical approval for this study was granted by the Course Organisation Group of the Doctorate in Clinical Psychology at the University of Edinburgh (Appendix I). Advice was also sought from the appropriate National Health Service (NHS) Ethics Committee who indicated that NHS ethical approval was not required, as the research was taking place through an external organisation (Appendix II). However, as the research was being conducted by an employee of the NHS it was still necessary for the research to be granted approval by the NHS Research and Development Department (Appendix III).

2.2.2 Possible Ethical Issues

It was recognised that there was a small possibility that the research interview might lead to parents becoming distressed in the course of discussing their experiences. It was decided that, should this occur, the researcher would initially use their clinical skills to try and manage the situation at the time. However, in the event that further support was required, parents were to be redirected to the voluntary organisation through which they were recruited. The organisation was considered to be in the best position to provide advice regarding further appropriate support. Additionally, having offered to conduct interviews at participants' homes, it was recognised that, although unlikely, there might be some risk to the researcher's safety. Accordingly, the lone working policy of the employing NHS trust was consulted. In all cases where an interview was being conducted at a participant's home, the address and telephone number of the location were left with a third party. The researcher indicated the approximate time they anticipated completing the interview and arranged to

contact the aforementioned person to advise them as soon as the interview had been completed. The participant's name was not included in the contact details, and these were destroyed as soon as possible following completion of the interview in order to preserve confidentiality and anonymity.

2.2.3 Informed Consent

Prior to conducting any interviews, including those in the pilot study, participants were provided with a description of the study and an opportunity to ask any questions. All participants were made aware of potential ethical issues by way of the participant information sheet (Appendix IV). Participants were asked permission for their interview to be audio-recorded and later transcribed with the removal of any personal identifiers. They were advised that the audio-recordings would be destroyed upon completion of the transcribing. It was agreed that all identifying information would be removed from the written transcripts before being archived for five years to support any subsequent efforts to publish the research. All participants provided written informed consent before interviewing commenced (Appendix V). At the time consent was obtained, participants were initially assigned a code that was used to identify their interview. During transcription all participants, and any other people to whom they referred in their interviews, were assigned pseudonyms which were used in the final reporting of results.

2.2.4 Dissemination of Results

All participants were sent a summary of the results from the analysis of their own interview and from the integrated analysis of all the interviews. Unfortunately, time constraints meant that it was not possible to do this during the analysis process. However, this information was provided to

participants as soon as was possible following completion of the analysis. A copy of the full research report was provided to the voluntary organisation for consultation by any interested staff and service users, and a copy was offered to each of the participants. The potential for publication of a journal article is to be considered.

2.3 Participant Recruitment

Participants were recruited through a local voluntary support organisation that provides a variety of support services for families of children with autism spectrum disorders. Following consultation with the research consultant of the organisation and the play scheme leader, it was agreed that it would be most appropriate to recruit through the play scheme. The play scheme provides respite support to parents for one day of the weekend on a fortnightly basis, with sessions held on alternate Saturdays and Sundays. This meant there were four different groups from which potential participants could be recruited. The only inclusion criterion for participation was that the child had received a diagnosis of autism. It was decided that parents of children with related diagnoses such as Asperger's Syndrome or another non-specific Pervasive Developmental Disorder would be excluded. This decision was made on the basis that the criteria of the different diagnostic categories are relatively distinct and, as such, they may be associated with qualitatively different experiences. It therefore seemed pertinent to focus on only one diagnostic category to maximise the homogeneity of the sample.

A recruitment information pack for potential participants was developed which contained an invitation letter, a participant information sheet and a contact details sheet (Appendix IV). The researcher attended the play

scheme on two consecutive Saturdays, whilst on the corresponding Sundays it was agreed that a member of staff from the play scheme would distribute an information pack to parents of children who met the inclusion criteria. Twenty recruitment information packs were distributed. Any parent who expressed an interest in participating was then contacted by telephone to discuss the research further and organise a suitable time to meet. At the initial meeting, consent was also discussed and obtained in writing, before proceeding with the interview.

2.4 Data Collection

During the initial phase of the research, prior to any interviews being conducted, the researcher spent time engaging with some of the available literature published directly by parents. Hughes (2003) and Moore (2005) were especially helpful in orientating the reader to the complexities of life with an autistic child. Both of these accounts offer the reader a privileged insight into the world of the author and their family. The importance of this was two-fold. Firstly, it allowed the researcher to begin developing an understanding of the key issues inherent in living day-to-day with a child who has autism. Secondly, this understanding led indirectly to enabling the researcher to be more empathic during the actual interviews, thus facilitating rapport between the researcher and the parents. A preliminary literature review of the extant research on parents' experiences of having a child with autism and other developmental disabilities was then conducted before developing a semi-structured interview schedule (Appendix VI). Development of the interview schedule was also informed by the literature on IPA methodology (e.g. Smith & Eatough, 2007). After consultation with an independent advisor and the research consultant at the voluntary organisation, slight modifications were made to the wording of selected

questions. The schedule was then piloted with two participants to directly evaluate the adequacy and sensitivity of the questionnaire. The data obtained from the pilot interviews were meaningful and appropriate to the aims of the study. They were therefore included in the overall analysis, along with the data obtained in the five subsequent interviews. Following an introductory question about their reasons for participation, parents were asked to 'tell me about your experience of having a child with autism'. The researcher then used appropriate prompts to explore different areas of the parents' responses. The interview was terminated when it was judged to have come to a natural conclusion. At this point two additional questions were asked to give the parents an opportunity to add anything else they wished to say and, finally, to find out what the interview experience had been like for them. Before commencing the interview, participants were asked to complete a short questionnaire to provide the researcher with some background demographic information (Appendix VII).

Interviews ranged in duration between 45 minutes and two hours and 20 minutes. Three interviews took place on the premises of the voluntary organisation (one with both parents), three at the participants' homes (one with both parents), and one at the participant's place of work. It is relevant to note at this point that there may have been some impact of the location of the interview on the interview experience for the participants. In the case of the first interview for example, which took place at the support organisation, there were some brief interruptions which may have affected the participant's engagement with the interview process. Two of the interviews at participants' homes were also subject to brief interruptions. Furthermore, it cannot be ruled out that interview setting had a more implicit effect and

that, where participants were interviewed in their homes, they felt more relaxed and consequently this was reflected in the content of their interviews.

Immediately after each interview, context notes were made which contained information on the interview experience from the researcher's perspective, and any initial thoughts on the participants' experiences and their accounts. These context notes were used to inform the subsequent data analysis as well the researcher's reflexivity. Reflexivity was also informed by the use of a reflexive diary at key points in the research process.

2.5 Participant Characteristics

Twenty recruitment information packs were distributed, with seven parents indicating an interest and subsequently taking part. As the participants were recruited from within a small community, limited demographic information is provided for the group as a whole in order to minimise the likelihood of breaching confidentiality. Participants comprised four mothers, one father and two heterosexual parent dyads. With regard to the children with autism, three were aged 11 years, three were 12 years and one was 15 years old. Six of the children were male, one was female. Average age at time of diagnosis was just under 3½ years (range 2 years to 5½ years). All of the parents and their partners were aged in their 30s and 40s, and in all but one case the mother was the main caregiver. In the remaining family, the parents took joint responsibility for care giving. In five cases the main caregiver worked part-time outside the home, in one case full-time, and in one case was not in paid employment. Six of the children with autism had siblings, whilst one was an only child. In those six families, two of the children were the youngest, two were middle children, and two were the eldest. With regard to schooling, four of the children were in special education, whilst the

remaining three attended mainstream school with special education support. Six out of the seven children had been diagnosed as having learning disabilities.

2.6 Data Analysis

Five of the interviews were transcribed by the researcher, while two were done by a colleague who was cognisant of the requirement for confidentiality, and who was not involved with any other part of the research process. These two transcripts were carefully checked against the audio-recording for quality and content by the researcher, thus ensuring familiarity with their content. Interview data was organised using the *Nvivo8* software package. In keeping with the traditional IPA approach, each transcript was analysed individually before any consideration was made of similarities or differences across the group experience. Prior to commencing analysis, each transcript was read through in depth so that the researcher could further familiarise herself with the data. During this process, anything interesting or significant about what the participant had said, or appeared not to have said, was noted as part of the initial coding process. This is akin to the 'left-hand column' aspect of the traditional IPA method (e.g. Smith & Eatough, 2007). The second stage of analysis was completed using *Nvivo8*. Transcripts were re-read and the initial notes were used to inform the coding of concise phrases which represented units of meaning that captured the essential quality of what was found in the text. These units were identified as emergent themes that represented the actual data at a more abstract level, and were equivalent to the 'right-hand column' aspect of traditional IPA (e.g. Smith & Eatough, 2007). The emerging themes were then considered as a whole and organised into interconnected hierarchies, with memos being produced parallel to this process that contained the researcher's thoughts

about why these themes had been identified. Once all interviews had been individually analysed, the identified themes were considered together and an overall group analysis was produced. This approach to the analysis was chosen to exemplify the aim of IPA of valuing participants' experiences and endeavouring to make sense of these individually before exploring the commonalities and differences across the participants' experiences. A sample of coding from one interview is provided in Appendix VIII.

2.6.1 Validation and Reliability

Short sections of two transcripts were analysed by a person independent to the research to determine inter-rater reliability, which was deemed to be satisfactory. In addition, the researcher had regular contact with an external supervisor experienced in qualitative analysis to review the research. This contact focused on discussing the analysis, in particular reviewing the development of the coding framework, which enhances the reliability of the findings. Related issues such as reflexivity were also discussed. Willig (2001) suggests that providing feedback to participants and giving them the opportunity to comment is considered to be a mark of quality in qualitative research design. Unfortunately, time constraints on the research process meant that it was not possible to send participants a summary of the results from the analysis of their own interview and from the integrated analysis of all the interviews during the analysis process, and thus the researcher was unable to validate the data in this way. It is acknowledged that participant validation would have enhanced the quality of this research. However, it is intended that participant feedback will be sought as soon as time allows.

3 Reflexivity

The context specificity of IPA allows the researcher to place themselves in the context of their interviews and analysis, a position from which there is prime opportunity to be reflexive. One way of achieving reflexivity, and thus increasing the transparency and integrity of the research process, is to reflect on the thoughts and feelings associated with different aspects of the research process and consider any interactions that may have occurred. However, Parker (2005) defined reflexivity as 'a way of working with subjectivity in such a way that we are able to break out of the self-referential circle that characterises most academic work' (pp. 25). In this approach to reflexivity, Parker is encouraging us to think about the social organisations we belong to, the types of people we are, and the histories we have when we engage in research. Thus, Parker's sense of reflexivity concerns power and what it means to be who you are in relation to your participants. This chapter aims to account for both of these approaches to reflexivity.

3.1 Achieving Reflexivity

From the very beginning of the research process, I⁵ endeavoured to pay attention to, and note, the thoughts and feelings that I was experiencing in relation to my research. I considered the experience of the interview process itself and the subsequent analysis to be particularly important, and thus recorded my impressions of the interviews immediately after their conclusion. Where interviews took place at a participant's home or office, I did this when I returned to my car; but where interviews were conducted at

⁵ Given the subjective nature of the reflective process, the researcher determined that it was appropriate to write this chapter in the first person.

the play scheme premises, I was able to make my notes before leaving. My notes included things such as, how well I thought the interview had gone, any thoughts that were occurring to me during the interview and, in some cases, initial themes that seemed to be apparent. I referred to these notes during the analysis of each respective interview to consider how these initial thoughts fitted with the actual data and the results of the analysis. Where appropriate, I discussed particular thoughts or feelings with my supervisor to facilitate the reflective process. What follows is a summary of my reflections on the research process itself, from initial conception of the research topic to the analysis. The reader is asked to respect that the information shared here represents my own personal experience and interpretations.

3.2 The Early Stages

The decision to focus on autism was initially influenced by my experiences of working with children with autism, and their families, during the course of my professional training. These experiences included contributing to diagnostic assessments and working with families requiring advice and support in managing the behavioural symptoms of their child's autism. These experiences gave me an insight into the challenges presented in raising a child with autism and I was interested to explore this further. Although there is a vast amount of research into autism, I became aware that little attention has been paid to what it means to be the parent of a child with autism. I found this surprising, given the significance of the role of parenting in attempting to 'normalise' the life of a child with autism. While reviewing and summarising the available literature it also became apparent that, in some cases, the results of previous research were not as focused as the title might suggest. This led to some rather arbitrary decision-making about

how to subdivide the literature, but ultimately made it more manageable. This also led to some doubt about whether the correct decisions had been made, and in the end I relied on my instinct.

In the course of my literature search, I found a paper by Stainton and Besser (1998) which reported results of a qualitative study exploring the positive impacts of children with an intellectual disability on their families. I subsequently identified reviews of other work in this area by Summers *et al.* (1989) and Hastings and Taunt (2002) which inspired me to think about how this might apply to raising a child with autism. I was keen to focus on exploring the positive aspects of parenting a child with autism. However, a colleague experienced in IPA advised me to focus on exploring general experiences, as a focus on positive experiences would be too leading. During the majority of the interviews the parents did reflect on the positive aspects of their experiences. However, I am aware that where this did not arise spontaneously, I sought to explore this with them. I believe that many people in the wider community, and possibly also a large number of professionals⁶, tend to perceive that having autism is accompanied by many negative consequences. It is the behavioural symptoms in particular that may prompt parents to seek professional advice. It is also these behavioural symptoms that society at large sees displayed when a child with autism is experiencing difficulty and frustration in trying to relate to their environment. I was keen to challenge the perceptions related to this and find evidence that demonstrated that children with autism can contribute richly to their family.

⁶ Please note this is the author's personal opinion.

3.3 In the Midst

3.3.1 Participant Recruitment

During my recruitment sessions at the voluntary organisation, I was conscious of the fact that I was an 'outsider': I was not the parent of a child with autism, and I would most probably be identified by my role as a health professional. I was also aware that I had come into this environment specifically to meet parents, some of whom were going to be passionate about their experiences of autism. At times I wondered if I was somehow exploiting their passion to meet my own need to recruit participants. Despite a lot of interest, potential participants were not confirming their intention to go ahead with an interview. I talked this through with my supervisor who suggested that I could be more robust in trying to recruit people and that I probably was not being as 'pushy' as I thought I was. It was helpful to realise that whilst people were expressing a genuine interest in taking part, they did not share my sense of urgency because they were not constrained by the same time demands as I was.

3.3.2 Interviews

After I had completed the first interview, the topic took on a new sense of importance for me. I think this was partly due to me feeling appreciative and humbled as the participants shared some very personal experiences. It was also partly about my sense that some of the participants had high expectations of me and how I would make use of the information they were sharing. As I progressed through the interviews, I was aware that, although there were some similarities in their content, each felt as though it had quite a different focus.

During the interviews I was aware of the ambiguity of my dual clinician-researcher role, and at times it was a challenge not to respond to certain things that the participant said. Whereas a clinician will focus very much on individuals, I was, as a researcher, trying to maintain an overall focus on the collective nature of the participants' experiences. It was also important to ensure that I was not leading the interview in any way. One of the participants was a similar age to me, and although I do not think this impacted on the interview, it made me reflect on the uniqueness of people's lives and experiences, and the different paths that we all take. I was aware at times of potential socio-economic or educational differences between myself and participants; however, as far as I could tell this did not impact on the interview. Certainly, from my perspective, these factors were irrelevant as the most meaningful thing for me was that someone was prepared to share their personal experiences with me, a stranger. As far as I can recall, none of the participants asked me about my own experiences with children or autism. I wonder if this is reflective of their own motivations in wanting to share their stories and improve society's understanding of autism. Perhaps the important thing for them was that someone wanted to listen, and the specifics of who that was were less important.

3.3.3 Analysing the Interview Material

Analysing the interviews presented various challenges, such as the difficulty of analysing each interview independently without being influenced by any of the previous analyses. When analysing later interviews it was hard to prevent previously identified themes coming to mind and influencing the decisions I was making. Conversely, it was tempting when analysing later interviews to want to go back and amend aspects of completed analysis, which usually occurred when I recognised commonalities in people's

experiences. It was also important to be mindful of how the literature I had read in preparing the research, and the knowledge and experience gained during my professional training, may be impacting on how I made sense of the interview material. Another aspect of analysis I noticed was that how to classify and organise the themes often seemed a somewhat arbitrary decision. I realised that some subordinate themes could just as easily be placed under one super-ordinate theme as under another. As there was often overlap between the themes, the same themes could be organised in several different ways and still make sense. I came out of the analysis with a deep respect for the participants and the experiences that they had lived through and shared.

4 Results

The aim of this chapter is to present the key findings from the analysis in the context of the original aims of this research. Following this, the analyses of the individual participants' interviews will be reflected upon.

4.1 The Meaningful Aspects of Raising a Child with Autism

Two of the original aims of this research were to explore which aspects of raising a child with autism are most meaningful for these parents, and whether raising a child with autism impacts on the family system and social and work circumstances. The experiences that the parents in this study described as meaningful for them were, by their nature, interlinked with the effect that their autistic child has on the family and on the wider social systems around them. It was therefore somewhat hard to assign these experiences definitively to either aim, and thus they are presented together. Analysis produced three core themes, each with sub-themes, which were relevant to these two aims⁷:

- Autism as a journey;
- What it means to live with autism; and
- Negotiating the social world.

These core themes and their constituent sub-themes will now be examined and illustrated using examples.

4.1.1 *Autism as a Journey*

The idea of autism being experienced as a journey featured strongly across participants' stories and was reflected in the structure of their narratives. In all but one case, the participants responded to the question 'tell me about

⁷ A summary diagram of the main themes identified across participants' experiences can be found in Appendix IX.

your experience of having a child with autism’ by going back to the time of diagnosis. Their stories then developed in a way that suggested there were several key stages that were inherently meaningful to them in their experience of raising a child with autism. These stages were represented by five sub-themes, which are summarised in Figure 1.

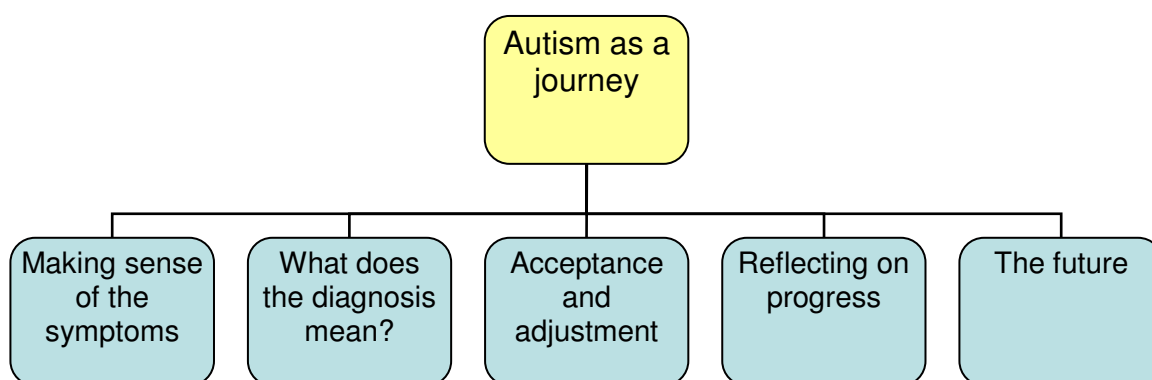


Figure 1. Core theme *Autism as a Journey* and related sub-themes

4.1.1.1 Making sense of the symptoms

Making sense of the symptoms represents the first part of the journey that these parents underwent. Participants described recognising that there was something different about their child. Often these differences became evident because their child was displaying difficulties interacting with their environment, or because there was a sibling whose normal development highlighted the autistic child’s problems.

The older he got during that time you knew there was something different by his behaviour, you know because he went into mainstream, you know you thought ‘no, there’s something not right’, you know, with his behaviour and things like that. (Jenny)⁸⁹¹⁰

⁸ All names used in this chapter are pseudonyms.

⁹ All transcripts were typed as spoken by the participants. The examples used will therefore contain grammatical inaccuracies.

We knew there was something wrong at age 2 or 2½. He wasn't speaking, his understanding was very poor...¹¹and as usual the grandparents were saying oh he's just slow, but I wasn't very happy you know, all the assessments he went to he just wasn't coping. (Anna and Paul)

We had a second child and it was actually reasonably early on in the whole thing that it became quite apparent that the development of the younger son appeared to be much more robust than Craig. It got to the stage where Jack was doing things and you were thinking 'gosh, it's only a couple of minutes since Craig did that.' (John)

The participants then went on to talk about their search to find answers, which meant exploring a range of alternative explanations before autism was even considered. In many cases the search started with speech or hearing difficulties being proposed as the explanation for their child's difficulties.

In the very beginning we never thought that Peter had autism, we thought he had a speech impediment. (Jenny)

Before she was diagnosed...erm...and I felt that was a horrendous time because obviously we knew that there was something but we couldn't...well then she was diagnosed with a hearing problem so we just put it down to the hearing problem, and the speech as well that's why the speech was delayed. (Sarah and Alan)

This search for an explanation indicated that there was often a protracted period of assessment until autism was finally diagnosed. The sense-making process also continued for some participants after diagnosis had been given. As part of the sense-making process some of the participants referred to the lack of fit between aspects of their child's personality and the diagnostic

¹⁰ A comma is used to indicate a short pause in speech.

¹¹ Ellipses are used to indicate either a prolonged pause or a portion of missing text.

criteria. In particular, some participants portrayed their children as affectionate and empathic, two characteristics which they suggested are incompatible with how the diagnostic criteria suggest a child with autism might present.

I don't think none of us expected...we didn't ken¹²nothing about autism anyway, I don't think we expectedmy only understanding was that they weren't cuddly, and you know but Jason was a cuddly, affectionate boy. (Anna and Paul)

Autistic children aren't supposed to be affectionate...well, that's a lot of rubbish, I don't believe it because Mark is the most affectionate child, out with his problem he is very affectionate, he'll come up and he'll give you a cuddle and say that he loves you. (Jane)

In some ways Craig demonstrates classic autistic traits and in other ways he's not at all classically autistic, so for example he's very, very demonstrative, very affectionate, empathises a lot with people, which is not particularly classic autistic. (John)

These examples illustrate the uncertainty that can accompany the experience of autism and which often re-surfaces at later points in the journey. These times of uncertainty were often characterised by difficult emotions, which in some cases led the participants to question their own parenting skills as they became desperate for an answer to why their child was having difficulties.

¹² Transcriptions of the conversations include terms which are part of Scottish dialect. These terms were left in as they convey a sense of how the participants struggled to understand and explain what was happening.

Before she was diagnosed...erm...and I felt that was a horrendous time because obviously we knew that there was something but we couldn't...I personally thought that it was me. I thought I wasn't coping, I thought it was maybe...erm...I just thought this was like...because I have a son that's classed as 'normal'. (Sarah & Alan)

4.1.1.2 What does the diagnosis mean?

Understandably there seemed to be a sense of enormity and significance attached to the participants' descriptions of what the diagnosis meant to them. It is clear that their child's diagnosis was a defining moment in their lives and one which many of them still recall with great clarity. This was reflected in the fact that, when asked to discuss their experience of having a child with autism, most of the participants immediately went to the beginning of their story and recounted their journey to diagnosis. They reflected on how they got to the point of receiving a diagnosis for their child and talked openly about what this meant for them. In many cases the participants equated receiving their child's diagnosis of autism with the experience of bereavement. The participants described their sense of bereavement in the context of suddenly losing the future that they had imagined for their child.

I remember the feeling of, it was like bereavement really, you'd lost all your expectations. My God, you ken you had just taken it for granted before the diagnosis that Jason would just grow up like the rest of them, get married have a family and suddenly you were told. (Anna and Paul)

You don't know when your child is born that they have got autism so your mind is thinking of, you know, of brothers and sisters playing together, of going to school, of getting married or whatever and when you are given this news, you've then got to come to terms with what does this mean. (Gail)

This period of bereavement was associated with feelings of devastation for some participants, whose emotional descriptions of the grieving experience indicated the sense of absolute loss that they experienced.

It was like a bereavement...funnily enough, it...it...I was absolutely devastated at the time. I thought 'oh my goodness, this is just terrible, this is...' I couldn't believe it. (Jenny)

It's so devastating when you get told...it's like somebody's ripped your heart right out of your chest. (Jane)

Some participants also described the ongoing nature of their grief.

There was a...probably an ongoing almost sense of grieving about the whole thing as well. And definitely you, or we certainly feel, and keep coming back to this feeling of kind of loss. (John)

These examples reflect the loss that the participants described they felt when their child was diagnosed. As well as losing the hope that their child's difficulties might be resolved, participants also referred to their loss of an imagined future for their child. The diagnosis meant a sudden loss of the potential for their child to achieve all the things that many of us take for granted, such as living independently, getting married and having children. In addition, despite the fact that diagnosis brought answers to explain why things were like they were, for most participants it also brought more questions.

One participant recollected the sense of loss she felt in response to her child's diagnosis in terms of the potential implications for whether she and her husband would be able to have more children, as a consequence of the

demands their autistic child placed upon their resources.

It kinda shut a few doors at that point because I thought 'God, we're probably never going to be able to have any more children' because at that point Philip took up a lot of our time. (Mandy)

For some, once they had processed their initial grief, it led to questions of what they were going to do next in terms of supporting their autistic child.

When you're first told I think you're just totally frozen inside you're just...you dinnae ken how to feel and then it was, I think it was a couple of days later it just hits you and 'oh god' you think, 'how am I going to help Mark through this and do the best by him?' (Jane)

Another participant related the uncertainty that was raised not only for her but also for her family, with regards to what the autism actually meant. She described not actually knowing what autism was, which made it difficult for her to help her family understand what her son's diagnosis meant.

When I went home and told my mum that, it was difficult to explain to them because they didn't know what it was. You know, it was like 'well what's that? What's that?', but I didn't know myself. (Jenny)

For other participants the uncertainty occurred more in relation to what their child's diagnosis meant for the family as a whole. There was a sense of wondering about how the autism was going to fit in with their lives, and how it was going to affect them all.

I had quite a bleak outlook for him when he was four and you know, and 'what are we going to do with him?' and I just couldn't think how he would fit into our life. (Mandy)

There were many additional factors which informed participants' experiences of receiving their child's diagnosis, including their interactions with professionals, the participant's own level of awareness regarding the possibility of autism, their knowledge of autism and how the actual delivery of the diagnosis was managed. Participants reported mixed experiences of the actual delivery of the diagnosis. Some participants referred to challenging experiences with professionals as they tried to impress upon them that they knew something was wrong with their child but felt they were not being listened to.

He wasn't forming words, it was stuck, the only word he was saying was no and I kept thinking, 'you know he's not sleeping either' and so I went back to the GP who said 'you're just panicking, you're tired, you're working full time'... I was like 'I think there is more than that', and he said 'no you're just tired, you know, you've got a lot on your plate, you're working full time'. I said 'I really think...' and he went 'no'. (Mandy)

For others the context of the diagnosis delivery was a difficult experience as they described sitting round a table with professionals who announced the diagnosis before the participant was then left to deal with this information.

They've got this board meeting kind of thing, and they turned round and said...and they all have their say, what they're wanting to say, and you're sitting there and you just feel totally out your depth, it's really quite scary if you like...and they just went round and said 'well I'm sorry but Mark has got autism and he's on the medium to high of the autistic continuum spectrum'. Well all this continuum spectrum I'm going 'what?' ken cos nothing had been really explained. (Jane)

For one participant the diagnosis came as a complete shock. The mother described an apparent assumption on the part of the professional that she

was aware autism was being considered, thus suggesting little preparation work was done during the assessment.

I remember the doctor said 'did you not know?', and I'm like 'no'. (Jenny)

In other cases the delivery of the diagnosis seemed, from the participant's perspective, to have been handled relatively well.

I think maybe with hindsight, you know these people see this kind of thing week in week out, and they get [?]¹³ and I think we had been getting warmed up from quite early on you know 'this might be the outcome'...so when it eventually came through I think it was done in very...as good a way as these things can be done. (John)

Parents may perceive their experience of the diagnostic process to be good, bad or somewhere in-between. However, it seems reasonable to assume that this perception will have some bearing upon their initial response to the news, particularly, perhaps in relation to the practical aspects of the diagnostic experience such as whether the parents were given appropriate advice and information on what to do next, how well prepared they were for the possibility of autism, and how they perceived the manner of the professional delivering the diagnosis. Having described their experiences of receiving their child's diagnosis of autism, which appeared to be a life-changing moment for them, the participants then went on to recount elements of acceptance and adjustment in their stories.

¹³ [?] is used to indicate that a portion of the audio-recording was unclear and the researcher was unable to determine what exactly was being said at this point.

4.1.1.3 Acceptance and adjustment

The participants all described a process of accepting and adapting to their child's autism in order to provide the best life they can for their child. Implicit in this theme is the notion that these parents regarded acceptance as a parental responsibility and not something that they could choose not to do. Acceptance seemed, from these accounts, to happen over time, as part of the autism journey, occurring naturally as parent and child grew and learnt together. Participants spoke about acceptance in the context of readjusting the expectations they held for their child's future and, in particular, how their child might develop.

I thought 'oh don't tell me that's what Jason's going to be like' and I thought oh, I just was distraught at the thought and Jason is like that now but the difference is he's grown and we've grown with him and accepted this whereas I was just seeing my cute little boy and this great big man almost flapping and it just horrified me. (Anna and Paul)

Once you've come to accept your child, and that's quite nice to when you come to that acceptance it's a gradual thing, you then see them in a different way and you see them, just the person that they are not as who you would hope that they were or wanting them to be different. (Gail)

Acceptance was also talked about in reference to coming to terms with the symptoms of the autism, and the behaviour that occurred in relation to this.

Craig will do certain things because he reacts in certain ways because of the condition...and you have to accept that, you have to deal with it as best you can but you know that that's what is behind it. (John)

For some participants, acceptance of the behavioural consequences of their child's autism also meant coming to terms with their own emotional

reactions to these, such as embarrassment, especially when they occurred in public places.

When he was little I was really embarrassed, I would, I couldn't, you know, I was like 'oh my goodness, get out this shop you're totally embarrassing me' you know, now, obviously because he's older, no it doesn't bother me at all...because I've accepted it. (Jenny)

I've accepted that he's loud, you know, and that's part and parcel of him and that's his character and you know, but sometimes it can be a wee bit embarrassing but he's just kind of phew [laughter]¹⁴, he's quite unaware that it's embarrassing. (Mandy)

The theme of adjustment and acceptance also reflects the realisation of participants that their lives as a family are different from families that do not include a child with autism. There is a sense of the participants redefining what 'normal' means for their family, and adopting a new perspective on their situation that helps them to normalise something that at first seems very unfamiliar.

He wasnae there and we thought 'this is strange' and we're sitting having a drink and thinking oh this is really, it was just totally relaxing and that's when it really hit home and I thought 'no our life is nae normal, that is normal but we are so used to...', but it just becomes normal and it just becomes a way of life. (Anna and Paul)

But you forget, we are obviously, I mean we are lucky but then again, as I said to Paul, sometimes when you're living it, it just becomes normal. (Anna and Paul)

¹⁴ Used to indicate the participant's expressed emotions or non-verbal communication.

Arguably, acceptance is an important part of these parents' experiences, and one that facilitated their ability to cope with their child's autism. For some of these parents though, acceptance is not just about being able to accept the autism, it involves being able to accept and adjust to all of the additional things that come along with autism, such as the fact that it is not a condition that will go away, and indeed will continue to present challenges as their child develops.

This is going to be for life, this is not something that's for a period of time then it's going to go away. We're always going to go through hurdles that you've just got to get over. (Jenny)

So, whilst these parents talked about coming to terms with the fact that their child has, and will continue to have, difficulties with communication and the social world, they also described the need to accept what that means in terms of the effect upon their own lifestyle and that of the wider family. In some cases this means accepting that as a couple you don't get as much time together.

We would like something that...probably be changed that we could have more time together but...its not happening so we've just got to get on with it. (Sarah and Alan)

For others it means sacrificing family holidays and losing contact with some friends.

We did lose touch with people and you know folk were going out without you but you know, what can you do... Those sorts of thing I find harder, you know, holidays and stuff like that we really miss out on but you know it's just too difficult. (Mandy)

Acceptance of their child's autism is something which clearly took time for the participants. It was also a process that was linked in closely with the other sub-themes of *autism as a journey*. For instance, it is easy to surmise that acceptance is influenced by *reflections on progress*, and *what does the diagnosis mean*. The meaning the diagnosis had for these parents, in terms of their future hopes and dreams for their child, also seemed to have some bearing on their acceptance of the autism. Over time, as parents were able to reflect on their child's progress, their adjustment to the autism was facilitated as they started to see new possibilities for their child's future achievements. These may not be the same as the ones the parents held before the diagnosis but, in the light of their child's progress, they are potentially more positive than how they perhaps imagined the future would turn out immediately following the diagnosis.

4.1.1.4 Reflecting on progress

The participants frequently made reference to their child's progress. This was often in the context of the expectations they had held for their child's ability to develop, and for their difficulties to show some resolution. When the participants spoke about their child's progress there was generally an implicit sense of their own progress too, of them making a journey with their child. This theme links closely with that of *positive aspects of raising a child with autism*, which will be discussed later in this chapter. Progress seems to represent a number of different ideas in these accounts. Firstly, progress was sometimes representative of a sense of pride in their child's achievement, something which perhaps goes unrecognised by others.

And he's come such a long way and maybe other people wouldn't see that he's come so far and probably they think he hasn't but to me he's climbed mountains. (Jenny)

I don't mind if people stare at us because I think 'you don't know the achievement for him being here.' (Gail)

Reflecting on their child's progress, in some instances, reflected a realisation for the participants of how far their child had actually progressed from the early parts of their journey.

I mean it's amazing how you forget, it's sometimes not until you start watching a documentary you think 'aye, I remember being there.' I mean he has progressed a lot. (Anna and Paul)

Progress was also synonymous for some parents with an improvement in the capacity of both the child and the family in their ability to cope with the autism.

I'm just over the moon, I'm overjoyed, I'm glad that Mark is finding things a bit easier and being able to cope with things a bit better...as opposed to, he is still withdrawn if you know what I mean he is still in his own little world...but he's coming out of it now. (Jenny)

Craig is improving in the sense that he's developing, not necessarily at the rate that other children are, but he is developing and he's...in some ways easier to deal with. (John)

There was also a sense from some participants that progress could be appreciated in even the smallest steps forward that their child made, which brought with them great joy for the family.

And I suppose every time she makes progress and things it gives you an even bigger satisfaction because you know that's like another hurdle that she's overcome. (Sarah and Alan)

Seeing Ian's progress has been a really positive thing for me. Every tiny thing that he does is just a massive thing you know the whole family sort of celebrate it. (Gail)

Finally, it was clear that seeing their child develop and progress allowed some participants to challenge their expectations of what the autism meant for their child.

He has come on more than I thought he ever would and his development has overtaken what I ever expected of him. (Mandy)

The final step in this part of the journey with autism is represented by the theme of *the future*. In some ways this has been implicit in all of the preceding sub-themes, but it also emerged as a theme in its own right.

4.1.1.5 The future

This theme relates to the participants' expressed concerns about their child's long-term future. From the point of receiving their child's diagnosis, participants spoke about their anxiety about what the future would hold for their child. It is evident across these accounts that, despite progress being made, there are still ongoing anxieties centred on the prospect that their child is unlikely to ever be able to live independently. The future was discussed by the participants in several ways. Some parents discussed it in the context of what happens when they, as their child's main caregiver, pass away.

I think the main thing is we're trying to make sure that she can be independent when she's older. It's her life skills that you're more focusing on. I mean academically, what she achieves she'll achieve, I'm not going to say she'll manage this or that, but as long as she can be able to be independent...you know we won't be here forever, so... (Sarah and Alan)

There's a sense...and I don't know how it will work out...but there is a sense of permanent dependence. It's like well, 'will we ever be able to do such and such?', 'will we ever get to the stage where we can leave Craig unattended at home?' Probably, but at this stage I'm struggling to see how. (John)

Concerns about the future were also sometimes referred to in the more immediate context of transition points, such as changing from primary to secondary school.

He's leaving school now and we're going on to the academy...so I'm back at the stage of where he first started primary thinking 'oh my goodness, where's he going to go' (Jenny)

Some parents expressed their concerns about what will happen when their child does eventually leave school. There was an implicit sense of concern in these statements about how their child's day will be structured without the routines of school.

You do worry about when they're older, that is my...because he's away to start secondary after the summer holidays, this is me now...it's hitting home 'oh what is he going to do when he leaves school?' (Jane)

One thing we were talking about the other day, that's starting to be a point of potential anxiety is with his...what happens post-schooling? (John)

When talking about the future, siblings were also acknowledged and, in particular, some participants were acutely aware of the likelihood that their

other children would be receptive to taking on a responsible caring role for their autistic brother or sister. However, these participants also shared their concern that their child without autism should not have to bear this responsibility.

He's got his sister Karen and he's got Richard but you cannae be expecting them to put their life around Mark, aye fit their life around Mark nae, they probably will but they'll want to do it but you dinnae want to feel, them to feel that you're making, that they've got to do it and its just trying to figure out what's best to, what he's going to do. (Jane)

These examples illustrate the significance of preparing for the future in raising a child with autism, and emphasise the constant nature of the uncertainty that these parents endure as part of their experiences. Even at times when things were fairly settled, it never seemed to be long before this security was lost, especially in relation to factors such as schooling and additional support services, where substantial time is often required to coordinate resources and put things in place.

Although he's only starting to make the primary to secondary transition, we're thinking down the line a little bit, well, what happens after school because there needs to be something... Our experience is suggesting... the earlier you spot these things and try and deal with them or try and find out what you need to do, the better. (John)

In summary, the theme *autism as a journey* represented the key aspects of the participants' experiences. This journey appears to be a complex and dynamic process which is very much an individual experience. Although commonalities emerged across the participants' stories in relation to the key aspects of their experiences, the way in which these were described to the researcher were unique. Following on from the core theme of *autism as a*

journey, the second core theme of *what it means to live with autism* emerged from the interview data. This theme is distinct from the previous one in that it is more directly concerned with what it means to live with autism from day-to-day.

4.1.2 *What it Means to Live with Autism*

This core theme reflects aspects of the participants' experiences of raising a child with autism that are more specifically related to the daily impact of autism. This theme focuses on the constant and ongoing nature of living with autism rather than key points in the journey. It reveals how the impact of the autism is integrated, or not, into the surrounding family and social systems around it. There were three sub-themes identified within this core theme, one of which had its own sub-themes. These are summarised in Figure 2.

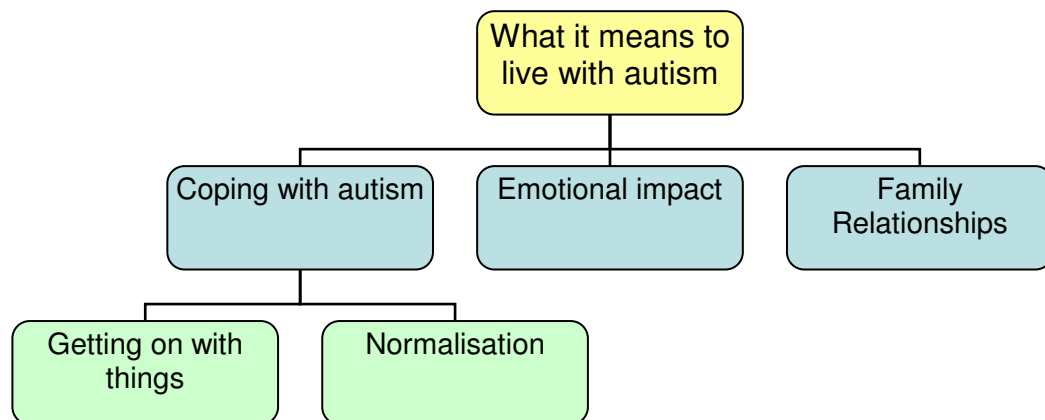


Figure 2. Core theme *What it means to live with autism* and related sub-themes

4.1.2.1 Coping with autism

Throughout their interviews participants made frequent references to coping strategies and how they manage the symptoms of the autism. Two sub-themes related to coping emerged from the data: *getting on with things and normalisation*.

4.1.2.1.1 *Getting on with things*

Firstly, there was a clear sense that, as the parent of a child with autism, participants perceived they had a responsibility to try and change things so that the situation is improved for both their child and the wider family. Thus, some participants conveyed a sense that they were thrown into having to cope with the autism.

Some people will say 'oh but we're not trained in working with children with special needs' and we're like 'well neither are we, but we've just been thrown into it.' (Sarah and Alan)

For others, however, there was a sense of them having made a conscious decision that they just had to get on with things and cope as well as they could.

Although I was devastated, I also thought 'Right! Now what do I do, how do I help him?' (Gail)

You've just got to dig your heels in and say 'right this isnae going to get the better of me', 'I'm going to do the best I can' and what will be, will be. (Jane)

But I think it's just something that you've got to do in that situation. You've just got to adapt to what you can and can't do basically. (Sarah and Alan)

The very nature of the symptoms seen in autism and the behavioural manifestations of these meant that being the parent of a child with autism presented a number of challenges for the participants, to them as an individual and to the wider family and its context. In order to cope with these challenges the participants described adopting a trial and error approach to identify strategies that would be effective in the management of their child's autistic behaviours.

You feel you're coping if you think I've tried that and I'll give that a go...some of the things for Ian didn't work and other things just worked a treat so you thought...but it is having that sense of being in control and being a wee bit more in charge of your life. With autism some of these things are so much out of your control that any little things that you can grab onto that means that you get an element of control back into your life again is great. (Gail)

You kind of work out what you can do and what you can't do and... stuff that you don't even try and do because it's just not going to work. (John)

It was also acknowledged that while it was important to understand the theory behind why your child is behaving as they are, at the end of the day what was required were practical coping strategies that will help everyone.

I mean theory is good too and you need to know to understand things but as a parent you're always desperate for the practical things that you can do. (Gail)

As part of being able to 'get on with things' some of the participants acknowledged the value of learning from other parents and the additional expertise they may be able to offer in regard to identifying effective behaviour management strategies.

A lot of what we learnt really was through other people and how to deal with Jason...or how to no deal with Jason... ken, oh we've been here and we found if you try this and try that and in the end that was more helpful than all your books and your professionals. Sometimes other parents going through it and you learn more from them. (Anna and Paul)

But I think just little things...maybe some other parents who have children...you get tips off of them...like 'I do that', 'oh well I do that', so it's really good to get other tips off of other parents. (Jenny)

Ultimately, there was an impression from the participants' stories that coping with autism on a day-to-day basis is something which was driven by the fact that this is their child, and therefore, coping with autism was something that has to be done. This was also highlighted as a potential learning experience for both parents and child.

You do have to get on with it, there's nothing else for you to do, you've just got to stick by him and see what happens next. And it is, it's like a whole new journey. (Jenny)

4.1.2.1.2 Normalisation

The concept of normalisation was earlier identified within the theme of *acceptance and adjustment*. Its emergence here, as a theme in its own right, recognises the importance of normalisation as an ongoing aspect of the participants' experiences which, for some, begins from the point of diagnosis. Within the theme of *coping with autism*, most participants described that they endeavoured to make the autism fit into their lives rather than their lives fitting the autism, as part of a search for re-establishing the normality of their lives. One way in which this was achieved was through treating their autistic child, as far as possible, just like they would treat their other children.

You've got to allow for the dangers and things, you've got to take that on board and deal with that but otherwise he just gets treated like any other child. (Jane)

It was also important to the participants that they retained as much of their previous family routine as they could.

Yeah, but he didn't take over our life did he. We still went on holidays. We know a lot of people who didn't take their autistic kids on holidays, but we always took Jason on holidays, weekends away and visited friends... (Anna and Paul)

We trained ourselves to just, kind of, try them anyway cos there's a temptation, when the kids are younger, just to stop doing these social things and not to go, em, but we've kind of made ourselves do certain things. (Gail)

Participants also spoke about their efforts to encourage their autistic child to come into their world rather than the other way around.

I want to get him out of his world and into our world. If I can even get a bit of him to do that then I feel like I've achieved something for him and he's achieved something for himself. (Jane)

We just felt that he had to fit into our world we weren't going into his. And he has. (Anna and Paul)

In some cases, participants described that these efforts to integrate their child into the family occurred almost in response to the frustration that resulted from allowances that were made for the impact of the autism at other times.

My wife will tend to be pragmatic about it most of the time but sometimes she'll have this 'we are doing this as a family. I don't care how much screaming there is, and how much stomping there is. We are going to do this as a family whatever it takes.' (John)

One mother was clear that actually there just came a day when she tired of the autism being the focus of their lives, and therefore made a decision that it was not going to be this way anymore, finding a way to re-normalise family life.

I went to all the talks but then I got to the stage, and I spoke to other parents, that I felt it was all the same and I got fed up of it and I felt I was eating and sleeping autism and I thought I just want to lead a normal life and forget about all this, ken everything was revolved around... (Anna and Paul)

These two sub-themes and their examples illustrate the many challenges that there are in coping with a child with autism. Nevertheless, there was a suggestion within the participants' stories that things got easier over time as they became more experienced. It seems that what some parents need are hands-on practical strategies that can be put in place to manage the behavioural symptoms of autism. However, the participants' accounts suggested that there are no 'one size fits all' strategies and trial and error is generally required to identify the techniques that work for a particular child.

4.1.2.2 Emotional impact

These results have already examined the participants' experiences of receiving a diagnosis, and acknowledged the sense of grief that often characterises this event. However, it became apparent during analysis that there was a secondary sense of loss to these accounts, which formed part of the participants' emotional experience of autism. In some cases feelings of

loss were related to the constant reminders about the things that their autistic child is unlikely to ever be able to do. The loss was further compounded in families with siblings who were developing normally and thus acted as a constant reminder of everything that the autistic child was unable to achieve. However, loss was particularly strongly reflected when one participant described the ongoing sense of loss that permeates his life, and has done since early on in his experience of having a child with autism.

Its almost like you have a child that's never ever going to reach anything like the potential that a child might have and it...there's a great kind of loss, not lost in the sense of had and lost, but loss in the sense of potential loss. That's quite difficult, and that featured quite strongly from early on. (John)

As their child ages ever nearer towards the point when ordinarily they might have been moving towards independence, a sense of loss was described by one participant as they reflected on the future and the reality of their child's ongoing dependence on them.

Things like that still hit home and you think, 'wouldn't it be nice just to be able to go', cos your families are getting up now and you should be able you know to, it winna be like that for us ken. (Anna and Paul)

This theme also reflects the continual conflict of emotions that can arise during the course of parenting a child with autism. The participants' accounts conveyed a strong sense of having to find a balance between different extremes of emotion that may occur in response to specific events or aspects of their experiences. The emotional impact of the autism and its symptoms varied according to the context. So, for example, where the participants were trying to manage the behavioural symptoms in a public

place, they talked about feeling an initial embarrassment, which was then compounded by feelings of guilt.

*I used to get so embarrassed and then I felt bad because it wasn't his fault.
(Jenny)*

At other times guilt was experienced in relation to spending time away from their child, engaging in activities that they know their child would have liked to be a part of.

But then we feel guilty because she loves shopping with us and we feel guilty because we've been shopping when she's not been there. (Sarah and Alan)

Alternatively, participants described experiencing guilt when their child's progress was interfering with an activity. For example, improved speech means the child is more talkative, but this might make some activities more difficult, like when the parents are watching a film.

We were trying to watch a film...and we were like 'we're trying to watch this', and straight after you say it you think 'I shouldn't be saying that, I've waited years for this' [Alan agrees]¹⁵ and then you feel guilty again, but it's good. (Sarah and Alan)

In addition to guilt, which seemed to be one of the most commonly occurring emotions, some participants described anxiety about whether their child was socially accepted.

He seems to be quite popular at school, which is good cos one day I drove past the school and he was sitting on a bench on his own and I was thinking 'oh nobody's playing with him at break times.' (Mandy)

¹⁵ Used to indicate communication between partners during the interview.

Some participants described the emotional meaning of their child's autism in relation to their child's difficulties in understanding and negotiating the social world, and their child's increased vulnerability as a result of this. For example, it was not uncommon for participants to refer to an unwillingness to let their child stay away from home because they were terrified something might happen to them.

The first time he got offered to go there I thought 'oh I can't let my baby go there' I was terrified, being too protective but then I thought to myself 'well it's not really fair of me to stop him going when I ken that he will enjoy himself'. (Jane)

I won't let him go anywhere or stay anywhere because I know [laughs] that I'm the only one, and it's terrible because he is getting older now, but no...very protective over him...I really am. (Jenny)

This sense of fear and protectiveness was also reflected when some participants talked about how their child's communication difficulties compounded their fears about their child's vulnerability. Within this, there was an implicit sense that other people cannot be trusted not to take advantage of their child.

...feel because sometimes like she doesn't really...come forward and tell you things it's like you're sc...sometimes you're scared...for her to be out, not out with anybody, but to be left, you know, without one of us there. (Sarah and Alan)

There was also a clear sense of the effect of time in helping some participants to re-evaluate their emotional experiences and look back on earlier events in a more positive way.

I mean I can laugh about that now, but at the time I remember inside I was like really angry. (Sarah and Alan)

Finally, one participant spoke about their experience of spending a significant amount of time with their child in the absence of the usual daily distractions when the rest of the family was away. The lack of these distractions highlighted for him the reality of his son's difficulties.

It was really kind of...sobering, I suppose would be the expression. You know you get to the end of the week and you feel really quite down. It just as I say just brings it home to you. It's erm...he is...he is quite severely disabled. So yeah, that's...that was...so you do have that...generally things are ok, but every so often you kind of get instances like that. (John)

These examples give some insight into the intensity of the emotional side of raising a child with autism.

4.1.2.3 Family relationships

The final sub-theme identified under the core theme of *what it means to live with autism* was *family relationships*. Participants talked about family relationships in the context of autism in several ways. Firstly, they spoke about their own relationship with their child and how the autism has impacted on the development of their parent-child attachment relationship. The examples cited below are also somewhat resonant with the concept of loss.

When you did things with him, or he looked at you and smiled or something it was a great feeling cos you felt like you were his mum again. (Gail)

I just thought I want to sit and tell you about the rocks or think about mermaids and...relationships are such a big part of life you know, and it's just, it's central to things and when you've got autism and you can't relate it's, it's ... you just feel like....like nothing, it's really hard to put into words. (Gail)

Relationships were also discussed in the context of the strains that the autism puts on the parental relationship. Again these strains varied; for some the autism caused additional stress as they disagreed over management strategies.

It was worse the kinda stresses cos sometimes we were at loggerheads before we even got there. It does put stresses on you, ken. When he kicked off and we'd end up arguing. (Anna and Paul)

For others the strain came in the form of one parent struggling to accept and cope with the autism in the early years, which consequently impacted on the parental relationship.

It did have an impact on us but we just managed to get through it and I suppose if you love each other and you want to be together you can conquer anything really...but it definitely wasn't easy. (Jane)

Some participants described the parental relationship being impacted as a result of them having to split themselves between their children as the most effective way of managing the autism.

So I guess to be honest I think probably the people that suffer most are my wife and I being pulled in separate directions, but we try to do as much as we can together. (John)

One of the couples who participated reflected on how their child's autism, in conjunction with a lack of available family support, has impacted on their ability to have time by themselves.

It is kind of difficult for us and our relationship [Sarah agrees], I suppose it's because we haven't got a lot of family that maybe can give us a bit of time out. (Sarah and Alan)

Secondly, several participants reported that having a child with autism had impacted on relationships within the wider family. For some participants this was due to the child's inability to establish a social connection with family members.

He didn't relate to anybody else in the family, that was very hard for Frank, he didn't relate to his dad at all, he didn't really acknowledge his grandparents and he just, kind of, looked through them or his aunts and uncles, and, that was hard for them as well, em, and it's hard for you cos you think your child is rude or something and it's not nice. (Gail)

In other cases participants reflected on the rarity of the family being able to spend time together as one unit because of the demands of the autism.

We'd all gone to pick Philip up and it was the first time we had all been in the car and we were laughing and joking with one and other and it's quite rare for the five of us to be out as a family at this moment in time. (Mandy)

For some the relationship impact was rooted in the family's lack of understanding of the autism in the early days following diagnosis.

Its all different now, we all understand Peter now, but yeah at the beginning it did put an awful lot of strain on the whole family, not just my mum and dad but my brothers as well, because they didn't understand either. (Jenny)

Finally, sibling relationships were discussed. Participants who had additional children reflected on the closeness of the sibling relationships which their children established, and the pleasure that accompanies these.

Oh aye, yes it's lovely to see when they do caper and sometimes Jason will copy him doing exercise but he's a big stiff lump but he enjoys it and you can tell he really does enjoy the time with his brother. (Anna and Paul)

They started playing and Karen her face, she was beaming, she was like 'my brother's playing with me' (Jane)

However one participant, despite the closeness of the sibling relationship, spoke about his awareness that for his developmentally normal child, there was perhaps a developing sense of responsibility for his autistic sibling. The participant also referred to a role reversal of the children, such that although the developmentally normal child was the younger, he was essentially in the role of the older brother.

He's technically the younger brother...to all intents and purposes actually he's the older brother, and as time goes on that becomes more and more the case. He definitely feels...I suppose as a family we kind of expect him to have certain responsibilities towards Craig. He inevitably is...as a sibling feels that he, it's not fair on him... 'why do I have to have an autistic brother?', 'Why have we got this?', 'why have we been stuck with this?' Having said that, they're very close. (John)

The social and communication difficulties of a child with autism often impact on their ability to form relationships in the way that most people understand meaningful relationships. However, the preceding examples also illustrate that there are wider implications for relationships.

4.1.3 *Negotiating the Social World*

The third core theme identified within the interview data was *negotiating the social world*. Other people and, in particular, negative social experiences, were central to many of the participants' accounts. This theme is comprised of two sub-themes which are shown in Figure 3.

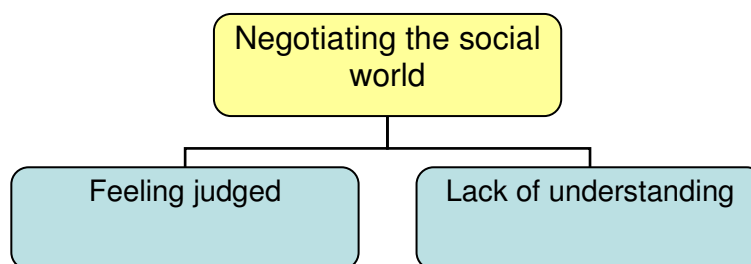


Figure 3. Core theme *Negotiating the Social World* and related sub-themes

4.1.3.1 **Feeling judged**

A feeling of being negatively evaluated by people around them featured strongly in participants' accounts, and was clearly a significant issue. The participants described a pervasive lack of awareness of autism in society at large, which led them to believe that the majority of people do not understand the behavioural manifestations of autism. This consequently resulted in the parents feeling they were being judged on how they managed their child's behaviour.

You can feel people's eyes on you, judging you, judging your child. (Gail)

I mean everybody used to stare at us and stare at him and I thought 'what are they trying to do', you know, 'why can they not live and let live?' (Mandy)

You seen people looking at him and it really got to me and I just left the trolley with all the shopping in it and just walked out with Mark, because I just couldn't cope with it. (Jane)

In some ways participants' experiences of being judged seemed equivalent to a perceived threat to self-esteem, due to an implied criticism of their parenting skills.

It feels horrible, em, there are days when you are stronger, and you're able to think 'You come and do it, if you could do any better' (Gail)

For some participants, this feeling of being judged also extended to a sense of not belonging to the social group around them, for example, other parents at the nursery or school.

Even although Ian's made loads of progress up to this point now, there's still a lot of occasions where you do feel an outsider, em, as families you feel like you don't belong in certain social situations. (Gail)

Parents didn't talk to me or they were two-faced, they would speak to me and say 'oh Peter is nice', but then, you know 'look what he's doing' sort of thing. (Jenny)

At times it was clear that this feeling of not belonging led participants to feel isolated.

There's other times where, you just, the isolation is, sort of, really bad then, you just feel like you don't belong at all. (Gail)

For others, feelings of being judged by the people around them led them to question whether they were doing something wrong. There was a sense that sometimes people feel pressure to ensure that their child fits in with society, rather than questioning whether society should make more allowances for their child.

I don't know sometimes you wonder if it's us that's wrong because you've got to conform to what society expects. (Sarah and Alan)

In the face of raising a child who, themselves, often lacks understanding of social situations, it was interesting that the participants described being so sensitive to what other people think. The lack of social understanding that often accompanies autism means that these children understand the social world very differently and may not be aware of some social judgements or have the same emotional response, yet their parents are still affected by them. This is perhaps further reflective of the *responsibility to protect* theme that has previously been discussed. As these participants' narratives progressed, they described becoming more able to deal with their experiences of feeling evaluated, and these became less bothersome to them over time.

4.1.3.2 Lack of understanding

Closely related to the concept of feeling judged by other people were reports from some participants that other people lack awareness of autism and do not understand the experiences they are going through. Other people's lack of awareness and understanding, in many instances, appeared to provide the context for the participants' experiences of feeling judged. Participants described occasions where people tried to empathise with them but, in actual fact, all that happened was that their lack of real understanding resulted in the participant feeling that their experiences were being diminished.

People saying 'oh yeah you know that's just the same as Murray, he does that, it's a nightmare', it lessens the effect of what you feel, it sort of diminishes it really in your own mind that they must think... as a diminished person, 'no you're not getting it at all' because yes Ian throws his cup over the thing and yes Murray might do that as well but Murray doesn't also do these other things. (Gail)

The same participant then went on to describe how, even when other people do look after her autistic son, the experience is divided between different family members and friends, with her doing a lot of preparation work with them, which essentially means that they still do not develop a true understanding of what it means to look after her son.

You sort of share it between them and they all manage, 'oh yeah its fine', and you sort of think 'I should really have left you without the list and then see how you get on.' Then they get a false impression of what's it's like for you to be that one person that manages all those things that everyone...you know I do all that when they're not here and it's that appreciation of trying to manage all of that. (Gail)

Another participant spoke about the lack of recognition from her son's school that he is a unique and individual child, and that all children, including those with autism, cannot be considered to be the same.

It's very frustrating because no-one, no-one seems to understand that when he goes into school, this child with autism, that no child is the same. (Jenny)

Similarly, she described the lack of understanding from the parents of the other children in her son's class who assumed that her son would be a disruptive influence.

The most tough time I think really was when he started school. Parents, parents didn't want him to be in mainstream because they thought that their children would be disrupted by him in class. (Jenny)

At times participants reflected that an apparent lack of understanding from others led them into sometimes challenging conflict with other people regarding how a situation or behaviour ought to be managed.

You have to say to people just go with me on this one and I know, I mean I was nearly in tears with this one but I knew it had to be done, you know, now I have to say to some people, look I know it looks hard, I know it looks cruel but we have to do it, it's for his own good but trying to get that across to people who have no experience is very difficult. (Mandy)

I get really angry with people like that and then they try and tell you what you should be doing with your son well I know Mark better than anybody. (Jane)

Other participants talked about their struggles with other people making assumptions about their child when they were struggling to cope with a public environment, and failing to consider possible explanations for their behaviour.

Even adults though I remember when she was younger and you'd be in the supermarket and she'd throw a strop and you know what...you could actually, practically heard some of them [both talking]¹⁶ 'what a brat they're being', and you're like [sharp intake of breath]. (Sarah and Alan)

In addition to their experiences of a general lack of understanding, several of the participants made reference to autism as a hidden disability. They described how this compounds their experiences of other people's lack of

¹⁶ Denotes that both participants were talking at this point and therefore it was not possible to be clear about exactly what was being said.

awareness of autism. There was agreement between several of the participants that, because autism is not an obvious disability in the way that a condition like Down's syndrome is, people fail to consider it as a possible explanation for their child's behaviour. Hence, strangers are much quicker to judge because there is not an obvious reason for their child to be behaving as they are.

Because he doesn't look as though he is disabled...I think that's the thing, if your child looks disabled people sort of think 'oh well there's something wrong there' but when you get a child who doesn't look...who just looks as they say normal, you know it's very difficult. (Jenny)

*People are very, almost like 'oh he's a little brat' kind of thing, cos they dinnae understand, because there's no physically...it's the, if he had down's syndrome or something like that then people are more understanding but because he looks **normal**¹⁷...as it is, people think that he's just misbehaving, and it is quite hurtful. (Jane)*

As part of the lack of understanding, there was also an acknowledgement from some of the participants that they want or need other people to understand what *their* experiences are like, rather than just focusing on their child. For some participants there was an acknowledgement that they would like people, family or otherwise, to be more cognisant of their need for their situation to be understood from their perspective. One participant spoke about how a lack of understanding from others caused her to feel isolated.

¹⁷ Bold type is used to indicate that this word was emphasised during the interview.

I did feel on my own because nobody understood what I...maybe selfishly what I was going through, it was alright to say 'oh well Peter's doing that and he's alright', but nobody ever said 'oh, how are you doing?' nobody asked how I was, and I used to get really angry. Because I thought 'well, no it's not just him, it is me as well.' (Jenny)

Another participant was clear that what she wanted from people was not pity about the fact that her child has autism, but rather understanding.

I don't want you to say 'what a shame for you', I don't want you to suddenly think 'oh here's a solution', I just want you to know what it's like so that you can appreciate it a bit more, so this is why I look so tired and why I can't come to things that you've asked me to. (Gail)

Overall, it seemed that when some participants spoke about a need for others to understand what their experiences are like, they were particularly looking for people to be able appreciate the depth of the challenges they face.

More importantly for me, are the kind of negative aspects of the experience cos I think that I want professionals and other people to understand what it is like for me... They need to know about the negative things, about the things that obviously get you down and that impact on your life and your child's life and your family's life. (Gail)

I feel that it's important that professionals understand what it's like living with a child with autism and I find they have limited knowledge and, you know, understanding of the problems that parents and family members face. (Mandy)

These examples illustrate the wide range of social experiences and attitudes that these participants have encountered. Not only have they come face-to-face with a general lack of understanding of their child's difficulties within wider society, but this is compounded for them by the fact that autism is a hidden disability.

4.2 Are there any Positive Aspects to Raising a Child with Autism?

The third aim of this research was to explore whether parents described any benefits to the experience of raising a child with autism. Across the interviews, parents described a variety of gains that they believed they had experienced as a direct result of the autism.

4.2.1 Positive Aspects of Raising a Child with Autism

Participants made reference to a number of positive changes in their lives that they attributed to their experiences of their child's autism. These gains were relatively abstract and tended to relate to changes in the participants' ways of thinking about the world, and their perceptions of what goes on around them. One of the positive things that some of the participants talked about was how having a child with autism had brought about a re-evaluation of their general outlook on life such that they had become: mentally stronger; more resilient in the face of stress; and more appreciative of life and the small things that can make you happy.

I think really to be quite honest he's made maybe me a stronger person, ken what I mean and probably a better person. I think that things that you just take for granted that you appreciate more because you have a different outlook. (Anna and Paul)

You see things through different eyes, you see the world differently...you just don't take anything for granted, you snatch any bit of happiness you get and you make the most of it because you know how it feels not to feel happy. (Gail)

In some ways it makes you much more appreciative of good stuff that happens. In other ways it makes you more resilient, because there are occasions where things happen and you think 'well, in the overall scheme of things this is just, it doesn't even register.' (John)

There were also references to how their experiences with autism instigated their own personal development. In some cases participants described that their experiences with their autistic child had increased their confidence and their tolerance, and also caused them to review their own tendency to be judgemental of others.

I think it's made me a better person actually. I stick up for myself a lot more, I don't let people walk all over me, I stick up for Peter...obviously because nobody else will... I'm a lot more patient. (Jenny)

One thing it's made me learn is never ever to judge anybody or make assumptions about people because you just don't know what's lying ahead of you. (Jane)

In another case, a participant recounted their experiences of meeting other people along the way, who represented positive social experiences related to her son's autism.

I've met some wonderful people that, other parents and also some people that have helped Ian, it reaffirms your faith in human nature. (Gail)

In addition to these more personal gains from their experiences, participants also frequently referred to what their child, as a person with autism, had brought into their lives, such as the feeling of joy about their child and the good times together as a family.

He's brought a lot of fun and laughter to our lives, ken what I mean, he has there's been a lot of good times, there's been loads of laughs and you've got to laugh ken, you're not laughing at him, ken what I mean but you have got to laugh I mean some of the things he's done, the things and the experiences. (Anna and Paul)

I mean she does give us so much pleasure, I suppose maybe at points...during the interview we've maybe reflected more on the negative side of things, but there is more positives than negatives. I mean she is brilliant is she? [Sarah agrees] (Sarah and Alan)

These examples illustrate the side of autism that perhaps is not so obvious to people who do not have first-hand experience of living with a child with autism; there can be many positive aspects to the experience.

It is clear from these findings that the experience of raising a child with autism is full of meaning for these parents. Raising a child with autism appears to be a complex process which starts from the point of realising that something is 'different' about their child. Only once adjustment and acceptance have occurred and effective coping strategies have been identified do parents seem to achieve a state of equilibrium from which they can reflect on the progress their child has made, and the positive contributions that the autism has made to their lives. This chapter will now go on to briefly reflect on the analyses of the individual interviews before the findings are discussed in the next chapter.

4.3 Reflections on the Findings from the Individual Analyses

As noted in the methodology, all interviews were analysed individually before being integrated to produce the key themes that represented the experiences of the participants as a group. During the individual analyses it

became apparent that although the themes that have just been discussed were intertwined across the participants' accounts, it was also the case that the participants had very different individual experiences. This is reflected in the main findings by the multi-faceted nature of many of the themes, and can also be seen in Appendix X, which shows a summary of the themes identified for each participant. This individuality of the participants' experiences did raise some issues during the integration of the individual analyses. In particular, there were occasionally themes identified for one participant that did not emerge strongly from the other accounts and, as a result, were not always incorporated into the final analysis. However, these themes are still represented in Appendix X. In some cases, where appropriate, strong 'individual' themes have been reflected in the final analysis. As an example, one participant's account of their child's autism was very much characterised by discussions of challenging experiences with professionals. While other participants made occasional mention of similar experiences, it was not to the same extent, and thus when it came to integrating the experience into the theme, it did not emerge as reflective of the group experience. However, this individual's experience is reflected within the themes of *what does the diagnosis mean* and *lack of understanding*, as these also contained references to challenging experiences with professionals from other participants.

The individual analyses also reflected where the participants were in their own journey with autism. In all cases, it had been several years since their child was diagnosed and, as such, the participants all seemed to have accepted and adjusted to the autism well. This is reflected in the identification of these themes in the final analysis. However, it was interesting to note the different ways in which participants had adapted. For

instance, in some cases external support services for their child were fought for and secured. In other cases this was not evident and the participants appeared to pragmatically accept the impact of the autism and get on with things as best they could. Either way, it was clear that all of the participants accepted the autism as part of their child, and whilst some acknowledged they would change it if they could, there was a clear sense that their child made a significant contribution to the family. As one mother said...

I am really proud of Ian now...and for a long time I used to wish the autism away cos I just didn't want that for him, for his future. I just thought god it would make life so much easier, but now he wouldn't be Ian if he didn't have autism, do you know what I mean, so it's just an acceptance of a part of him, he's just Ian and I don't want to not have Ian and I don't want to not be Ian's mum so I do accept warts and all the things about it...and that's a positive thing because it's helped me learn and work through things and realise that nothing is the end of the world. (Gail)

5 Discussion

The primary aim of this chapter is to consider the current findings in the context of the relevant literature. Analysis of the interview data culminated in the emergence of four main themes: *autism as a journey; what it means to live with autism; negotiating the social world; and positive aspects of raising a child with autism*. The key findings within these themes will be discussed with reference to the original questions that this research aimed to answer. These were:

- Which aspects of raising a child with autism are most meaningful for these parents?
- Does the experience of having a child with autism impact on the family system and social and work circumstances?
- What, if any, do these parents consider to be the positive aspects related to their experience of having a child with autism?

This chapter will also discuss the clinical implications of the current findings before highlighting potential areas for future research and reflecting on the research design.

5.1 Which Aspects of Raising a Child with Autism are Most Meaningful for Parents?

As noted in the previous chapter, the experiences that the parents in this study described as meaningful for them were, by their very nature, inextricably linked with the effect that a child with autism has on the family and on the wider social systems around them. As a consequence, this section will also implicitly answer the second research question; *does the experience of*

having a child with autism impact on the family system and social and work circumstances?

5.1.1 Making Sense of the Symptoms and Receiving a Diagnosis

It was clear from the theme *autism as a journey* that there are a number of meaningful aspects to these parents' experiences that constitute key points in the process of raising a child with autism. For instance, making sense of their child's symptoms, receiving their child's diagnosis and the emotions attached to this event all emerged as important. The significance of these aspects of raising a child with autism had previously been identified (Fleischman, 2004; Hutton & Carron, 2005; Midence & O'Neill, 1999), and there was strong support within the current findings for grief, in particular, as the primary emotion related to diagnosis. In addition, the participants often also referred to an added dimension of feeling alone and without appropriate information about autism and what it means, which is similar to the findings of Whitaker (2002). Relevant to the sense of the child's diagnosis representing bereavement, the theme of *loss* also emerged as meaningful for these parents in relation to the daily experiences of raising a child with autism. This is in keeping with the proposal of Siegel (1997) that, following the initial grief reaction to the diagnosis, there is less likelihood of a complete resolution of this grief because of the pervasive and enduring nature of developmental disabilities. This was reflected within the current research as participants talked about the continual reminders they experience of what their child will probably never achieve.

With further regard to diagnosis, it was clear from some of the participants that their experience of having an autistic child who shows affection and empathy did not seem to fit with their understanding of the diagnostic

criteria. Indeed, although the criteria do refer to a 'lack of socio-emotional reciprocity as shown by impaired or deviant response to other people's emotions' (WHO, 1990) as one of the possible symptoms, it is not necessary that this is present for a diagnosis to be given. Nevertheless, an assessment of the child's ability to be empathic often constitutes part of the diagnostic assessment. It is perhaps the case that the diagnostic criteria have become misinterpreted over time such that it has become a common belief within society that autistic children are unable to show empathy or affection. Reflection on this could potentially open up an interesting discussion about our understanding of these terms themselves. What constitutes a meaningful level of affection or empathy? It may be obvious when a person lacks these abilities altogether, but how can a value be assigned to the degree of the ability? It was evident listening to the parents who described these abilities in their autistic child that their children could be affectionate or empathic in meaningful ways. However, it is also worth considering whether parents' expectations may affect the value or meaning they place in signs of affection or empathy in their autistic children? If they thought it was not possible, and then their child gave them a hug, for example, it is possible that they would value, or note it more, than if one of their other children had done the same.

5.1.2 Coping, Acceptance and Adjustment

Coping with autism also emerged as a particularly strong theme, evident in the accounts of all participants. These findings on coping were consistent with previous research (Gray, 2003; Hastings *et al.*, 2005a; Hutton & Carron, 2005), which has found that autism has both direct and indirect effects on the family. Participants in this study described the direct effects in terms of the behavioural symptoms of their child's autism, and their need for practical advice on how to manage these. Indirect effects of the autism were reflected

to some extent within the theme *family relationships* where participants spoke about how the parent-child attachment, parental relationship and wider family relationships had been affected by the autism. Additional indirect effects of raising a child with autism were encapsulated within the themes of *emotional impact* and *negotiating the social world*. As well as employing a practical approach to coping, participants also described adopting cognitive strategies such as adjusting their expectations, which is consistent with Glass (2001). For example, Sarah and Alan said,

We've never really set goals for Emma because we always felt if we did that and she didn't achieve them we'd end up disappointed. So, by not doing that I think it's helped us cope better [Sarah agrees], and when she is doing certain things...it's because we haven't set her any goals and it's like a bonus.

In addition to these adjusted expectations reflecting an effective coping strategy, they were also likely to serve as a function of adaptation and adjustment as proposed by King (2006) and Bristol (1987). By revising their expectations of their child, the participants were able to attach increased value to any progress their child made. In particular, King's identified themes of initial reactions to being the parent of a child with a disability, adapting over time, and changes in world views and values, were reflected in the narratives of the participants in this study. As part of the adaptation process there was a suggestion within the participants' stories that things got easier over time as they became more experienced at managing their child's autism. However, the emergence of *the future* as a theme and the anxieties that this represented maybe challenges this in some ways. Perhaps it was only when given the opportunity to reflect that the learning the parents had undergone became apparent to them.

Interestingly, the participants in this research made little explicit reference to emotion-focused coping strategies. This may be due to the structure that the narratives took, so that by going back to the point of diagnosis and what then followed, learning to manage the behavioural symptoms was the most meaningful aspect of their experiences. However, it seems reasonable to suppose that this was an emotionally stressful time for the participants and, accordingly, they experienced a variety of emotions. Perhaps it was the case that the parents were so busy meeting the needs of their autistic child that they did not have time to stop and think about their own needs. During one interview the participant became quite emotional and expressed surprise at this, reflecting that it must have been bottled up as they had never really had a chance to talk about their experiences. It would be interesting to explore whether this is the case for other parents of autistic children.

It was also interesting to note the relative lack of references to social support in participants' accounts. Whilst there was frequent mention of social relationships and the impact of the autism on these, the unique role that social support plays in coping did not emerge from the interview data as a strong theme. Certainly there were some references to family members having difficulty accepting the autism, which is in keeping with the findings of Hutton and Carron (2005). At least two participants recounted that their true friends have stuck by them throughout their experiences, whilst other friends disappeared. However, there was little elaboration on these experiences which, in hindsight, might have been interesting to explore. It may be that this lack of reference to social support reflects the stage of the journey that the participants were at, thus appropriate social support is something that has been negotiated and is now stable. Perhaps this theme

may have emerged more strongly if the interviews had taken place closer to the time of diagnosis.

As only two parent dyads participated in this research, it was difficult to get a coherent idea of any differential experiences of stress and coping. However, it may be possible to make to some tentative inferences. In at least three interviews the mothers referred to their partner's difficulty in accepting their child's autism, which was particularly related to the early years following diagnosis. In all cases, it was reported that the fathers had now fully accepted their autistic child and developed a good relationship with them. It seemed to be that there was something important about the child being older and having made some progression in their ability to develop social relationships, which made it easier for fathers to cope with their child. Related to this, it was interesting to note that in six cases within this sample, the mother was the main caregiver for the autistic child. This is consistent with Gray (2003), and perhaps adds some weight to the researcher's earlier speculation in the introduction that coping with an autistic child might be more reflective of the adoption of traditional gender roles, and what that means for level of contact with the child, rather than being related to true gender differences in the use of coping strategies. Of course, it may be the case that the reality lies somewhere in the middle. Further focused research is again required to be able to make any definitive statements about this.

5.1.3 Lack of Understanding from Others

This was a particularly strong theme for most of the participants and echoes the recent findings of the NAS (2007) report which highlighted ongoing discrepancies between the reality of people's experiences of autism, and public perceptions of the condition. However, these concepts have been

explored in more depth from the parents' perspectives in the current research.

It is interesting to think about the impact of the participants' social experiences in terms of the parental role and the journey the parents have gone through with the autism. As a parent, even with a developmentally normal child, there is a steep learning curve, and parents have to develop skill and confidence in their ability to parent their child effectively. As one participant said, prior to diagnosis when you are trying to make sense of what is going on with your child, one of things you do is question your parenting skills. To then go through the process of diagnosis and learn your child has autism means you have to supplement your established parenting skills with strategies specifically tailored to the autism. Participants reported that feeling judged by others is most bothersome in the early years of their child's autism. It seems plausible that the reason for this may be the fact that parents are trying to adjust to their child's diagnosis, while at the same time striving to parent their child in a way that accommodates the autism. This is likely to require substantial emotional resources, and so any perceived criticism of their parenting is perhaps interpreted as a threat to their self-esteem. When this perceived criticism occurs in the context of a society which by and large has little understanding of autism and what that means, it is easy to see why people feel judged, and why this is such an emotive experience for them.

Within the participants' stories there were also references to the need for others to understand them which did not necessarily relate to wider society. In some cases it was clear that there was a perceived need for husbands or the wider family to understand and appreciate what things were like for the

person who was the main caregiver. On some level this may relate back to the findings on coping strategies, and the gender differences that appear to exist there. Nevertheless, feeling that your own family do not understand or appreciate what you are experiencing may be an important contributory factor to the relationship strain that can occur when raising a child with autism.

The discussion has thus far considered how the current findings relate to the first two research aims. It is evident from this that, certainly for these participants, raising a child with autism is characterised by many meaningful experiences which interact to produce an overall experience which is incredibly complex. The discussion will now move on to consider the findings related to the third research aim.

5.2 What, if any, do Parents Consider to be the Positive Aspects Related to the Experience of Having a Child with Autism?

The results of the current study contribute to the emerging evidence base regarding the positive aspects of parents' experiences of having a child with autism. Certainly, as far as the researcher is aware, this study is the first to identify this theme within a sample specifically composed of parents of autistic children. Previous studies (e.g. Hastings & Taunt, 2002; Stainton & Besser, 1998) conducted research using mixed samples and, as acknowledged in the introduction, the nature of the difficulties associated with autism means that it may result in parental experiences that are qualitatively different from those associated with other developmental disabilities. The participants in this study talked about a number of gains that they believed had come from their experiences of raising an autistic child. These gains resemble findings identified in previous studies which have explored

positive changes in the lives of parents who have children with disabilities. For example, Scorgie and Sobsey (2000) and Stainton and Besser (1998) found that parents reported changes that included:

- Personal growth;
- Improved relations with others;
- Changes in philosophical or spiritual values;
- Increased sense of purpose and priorities;
- Increased tolerance and understanding; and
- Positive impact on others/the community.

Both of these studies recruited samples of parents whose children had a variety of disabilities, including developmental disorders, intellectual disabilities, visual impairment and severe multiple disabilities. Similarly, Green (2007) conducted a study using a mixed methods approach with 81 mothers of children with various disabilities including, cerebral palsy, spina bifida, head trauma and Down's syndrome. The author reported that, regardless of the socio-structural constraints associated with caring for a child with complex needs, most mothers perceived valuable benefits in having a child with a disability. Despite the heterogeneity of the samples, these themes are very similar to the ones identified in the current study, which in particular related to increased tolerance and understanding, appreciation of the smaller things in life, and changes in philosophical values. However, participants in the current study also referred to a sense of the positive value that the autism had brought to their child such that the autism was accepted as a part of their child, and that without it their child would not be the person that they are.

The participants in this study have provided further insight into what the experiences of raising a child with autism can mean. However, despite the commonalities that occurred across these participants' experiences, it is important to remain mindful that within these, there were experiences associated with raising a child with autism that were unique to a particular family.

5.3 Relation of Current Findings to Other Disabilities

Aside from the positive aspects discussed above, it is worth briefly considering how the current findings might relate to other elements of the experiences of parents who have children with other developmental disorders or chronic conditions. A brief summary of research exploring the unique challenges of Down's syndrome, fragile X syndrome and multiple disabilities is provided by Head and Abbeduto (2007), each of which will now be considered.

It has been said that individuals with Down's syndrome tend to be highly sociable and display lower rates of challenging behaviours, such as aggression and hyperactivity, compared to other developmental disorders (Antonarakis & Epstein, 2006). It is suggested that these factors are responsible for the tendency towards lower stress levels and higher levels of positive impact of the condition on the parents of these children (Hodapp *et al.*, 2003). Eisenhower *et al.* (2005) examined the relationship between maternal well-being and syndrome-specific behaviour in the mothers of children with either Down's syndrome or cerebral palsy. They reported that whilst the mother's of Down's syndrome children, on average, reported lower stress levels they reported increased maternal stress and behavioural problems over time. It has been reported that mothers of individuals with

fragile X syndrome appear to be at risk of poor psychological outcomes, with higher levels of stress and lower levels of well-being being reported than in normative samples, and mood disorders being common (e.g. Abbeduto *et al.*, 2004; Johnston *et al.*, 2003). Abbeduto *et al.* (2004) also reported that mothers of children with fragile X described more symptoms of depression and greater pessimism about their child's future than did mothers of children with Down's syndrome. The authors concluded that there is considerable variation in the well-being of mother's of children with fragile X which is related to differences in the behavioural challenges displayed by individual children.

Children with multiple disabilities include those who have physical limitations in addition to potential cognitive and behavioural impairments. In families of children with spina bifida, for example, increased psychosocial difficulties and family distress have been reported (Holmbeck *et al.*, 2003; Greenley *et al.*, 2006). These authors have also noted that members of families that have a child with spina bifida are associated with less cohesive and less engaging patterns of interaction among family members. The social consequences of raising a medically fragile (MF), (e.g. severe cerebral palsy, genetic conditions, sequelae of premature birth) or developmentally delayed (DD) child was recently explored in 20 families with school-age children (Rehm and Bradley, 2005). The authors reported that the main theme to emerge reflected the families' search for safety and comfort in social situations. This included: the need to anticipate and plan for the child's care; overcoming environmental, child-related, and attitudinal barriers; and finding social activities that were comfortable for all members of the family. The authors found that when safety and comfort could not be achieved, families often described limiting social activities or splitting the family so

that the MF/DD child could be cared for while other family members participated in social events.

It is difficult to draw any firm conclusions about how the experience of raising a child with autism compares to raising a child with any other type of disability. There is a vast amount of literature in this area, reporting findings that have emerged from the use of a wide variety of methodological approaches. Nevertheless, it seems reasonable to conclude, albeit tentatively, that some similarities exist between the experiences of parents of children with autism and those with other chronic conditions. However, it is important to note that the behavioural phenotypes of these different disorders may impact on parents and families in different ways and to different extents, resulting in condition-related differences in the mental health and well-being of parents and other family members (Seligman & Darling, 2007), as illustrated in the preceding discussion.

5.4 Clinical Implications of the Results

There are several important ways in which these findings may be relevant to clinical practice. Firstly, the findings regarding the significance of the diagnosis, and particularly its relative similarity to bereavement, could be used to increase awareness of the specific difficulties, such as feeling isolated, that parents might experience in the early days of adjusting to the diagnosis. Consequently professionals could perhaps take the lead from parents regarding the level of information and support that they would find most beneficial at this time. These findings also suggest that it can be important for clinicians to ensure they ascertain parents understanding of autism when giving a diagnosis and, where appropriate, consider preparing parents for the possibility of autism as a diagnosis during the assessment period. It was

also apparent from these parents that they wanted and needed practical ideas for managing their child's behaviour. Professionals working with different families of autistic children are in an ideal position to share strategies with other families who may be looking for such support. These results could also potentially be used as a training resource for staff working with families affected by autism in order to facilitate optimal levels of empathy and care provision for the family.

Secondly, the results acknowledge the impact that autism can have on family relationships and, in particular, the parental relationship. Loynes (2001) recommended that health professionals should be more aware of the strains that caring for an autistic child can have on relationships. Therefore, professionals working with the families of autistic children could support families to explore all potential avenues of support. In some cases it may also be appropriate to consider whether the parents might benefit from support specifically aimed at helping them to work through how the autism has impacted on their relationship, particularly given the acknowledgement that it is sometimes more difficult for fathers to adjust, and the consequential implications of this in cases where the mother is the primary caregiver. Related to this some of the participants pointed out that their own personal need to be heard and understood is often forgotten in the midst of their child's difficulties. The researcher would therefore suggest that, where it would inform clinical intervention, professionals could consider allowing parents an opportunity to share their own experiences of their child's autism.

These results support the findings of the NAS (2007) report highlighting the extent of public misperceptions of autism. Furthermore, the current research has highlighted the impact that public lack of understanding had on these

parents, particularly in the early stages when they were adapting to and learning to manage their child's autism. It is envisaged that the findings as a whole and, in particular, those related to the positive aspects of parenting a child with autism, could be a useful resource for the parents of other children with autism. Of course, which aspects of the findings to share, and at what time point in the parents' experiences it would be most helpful to do so, would be a matter of clinical judgement. These findings have also highlighted the value of peer support for these parents, and as such they could potentially be used to facilitate peer support learning experiences. Finally, the results highlight the uniqueness of any one family's experience of raising a child with autism. By bearing this in mind, professionals can do their best to ensure that the care they provide is tailored to the individual child and their family.

5.5 Future Research

During the course of the preceding discussion some potential areas for future research were highlighted. These include:

- How do parents view the role of social support in their experiences of raising a child with autism?
- How do the positive aspects of raising a child with autism interact with the other significant aspects raising a child with autism?
- What are the experiences of the non-primary caregiver/ siblings/extended family members in raising a child with autism?

The current research findings provide a valuable addition to the growing literature in this area. However, despite the ecological validity of these results they are perhaps most appropriately considered as a foundation for further research to build upon. Possibly the most sensible next step would

be to develop a questionnaire on the basis of the current findings, which could then be completed by a much larger sample of parents in order to determine their level of agreement with the reality of these findings. This would thus assess how well the current findings represent the wider population of parents of autistic children. However, there would also be value in doing further qualitative research in this area, perhaps using focus groups as a way of generating greater volumes of data from a larger sample.

5.6 Methodological Considerations

This section will consider the most influential aspects of the research design that could have been improved, thereby increasing the confidence with which the results can be interpreted. The reader is referred to the methodology chapter for a full discussion of the methods used.

Qualitative research does not routinely aim to produce results that can be generalised; rather it seeks to provide rich and detailed information regarding a particular phenomenon. Thus, while it is important to reflect on selection bias when interpreting the findings, it should not automatically be considered a weakness. Nevertheless, as reported in the methodology, the researcher attended the play scheme to recruit participants only for the Saturday groups and not the Sunday groups. Therefore, in some cases, the research information packs were put into the child's bag to go home with them. It is acknowledged that this was a rather passive way of recruiting and may have impacted on the number of participants. Furthermore, as part of the interview, participants were asked about their motivations for agreeing to take part. The primary reason given indicated that the participants wanted to be a part of something that could potentially help other people, both health professionals and the wider community, to

understand their experiences. This perhaps raises questions about the potential participants who chose not to take part and about whether their experiences are likely to be echoed in those of a group who were clearly motivated to participate. It is possible that the experiences of the people who chose not to participate were qualitatively different.

It is worth also considering the composition of the participant group: four mothers, one father and two parent dyads. Clearly this may have some bearing on the content of the interviews and the issues which were discussed. Particularly in the cases where parental dyads were interviewed, it is difficult to ascertain how one parent's account might have influenced the other parent's account. A final factor that may have influenced the results is that the participants all had access to some form of support, by way of the play scheme. Other families who have little or no support may have very different experiences from those reflected here.

6 Conclusions

The findings from this research indicate that being the parent of a child with autism is characterised by many meaningful experiences, several of which are particularly significant. For example, the journey to, and receipt of, their child's diagnosis was identified as exceptionally important for these participants. The results suggested that no aspects of the participants' experiences could be defined as *most* meaningful. Rather, they indicate that raising a child with autism is a complex and all-enveloping experience. Furthermore, there are complicated interactions between the different aspects of these experiences which reflect the ever-changing nature of the challenges of parenting a child with autism. Parents' experiences are influenced by the encounters that they and their child have with wider society and with the professionals they meet along their journey.

The participants in this study were looking to share their experiences in order to improve the understanding of others. In addition to contributing to our general understanding of what it means to parents to raise an autistic child, I anticipate that these findings will be valuable as a clinical resource for parents of children recently diagnosed with autism. Hopefully, these findings will also encourage clinicians to be more cognisant of the experiences parents have, and how these impact upon other areas of their lives. Above all, although there are aspects of raising a child with autism that are common across peoples' experiences, there are also many aspects that are unique to the individual child and their family.

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Appendix I

Ethics Approval from Course Organisation Group

Date: Mon, 10 Dec 2007 13:02:26 +0000

Subject: RE: Ethics query

Hi

Discussed at COG and agreed that it does not need to be seen by any other uni committees as it has been discussed by our in house ethics meeting. I wonder what the ethical issues she mentions are? Do you know how you might be able to get a quick idea of what she means?

Date: Mon, 10 Dec 2007 16:06:29 +0000 (GMT)

Subject: Re: Ethics query

Dear

Thank you for getting back to me so quickly upon your return. It is appreciated. I have been in touch with my academic supervisor and clarified the university ethical review process.

However, I wondered if you could tell me whether you were referring to any particular ethical concerns, over and above those noted in the proposal, when you said that there are ethical issues with the research?

Date: Wed, 12 Dec 2007 16:31:55 +0000

Subject: Re: Ethics query

Dear

Thanks for your email.

I think you have covered all the ethical issues in the application. I would just ensure that your participants are fully informed about what you are doing, that the research is part of a qualification and what you hope will be gained by this research.

Kind regards

Dr

Acting Scientific Advisor

Research Ethics

Appendix II

NHS Ethics

Date: Mon, 10 Dec 2007 08:37:37 +0000

Subject: Re: Ethics query

Dear

My apologies for not getting back to you sooner, I was off sick last week.

After discussion with the Chair of Committee 1, the feeling was that you do not need to come to an NHS Ethics Committee as, as you mentioned this is outwith our Remit. If you do want to submit it to us regardless of this we will be quite happy to look at it.

We would like to suggest that you do get ethical review from a university ethics committee as there are ethical issues which should be addressed.

Kind regards

Dr

Acting Scientific Advisor

Research Ethics

Appendix III

NHS Research and Development Department Approval
All identifying information removed

Date: 24 January 2008
Our Ref: 2008PC002

Dear

Project title: A Qualitative Exploration of Parents Experiences of Having a Child with Autism

Funder : University of Edinburgh

Thank you for returning a signed copy of the declaration as required under the Research Governance Framework. We have now received a letter from the University of Edinburgh confirming the role of sponsor for the above study.

This study is now registered with our office and has R & D management approval to proceed within NHS .

We wish you every success with this research.

Kind regards

Yours sincerely

Data Co-ordinator

Appendix IV

Research Invitation Letter

All identifying information removed

Participant Information Sheet

All identifying information removed

Formatting adjusted to facilitate presentation

Contact Details Sheet

Research Invitation Letter

January 2008

Dear Parent

I am a Trainee Clinical Psychologist in my final year of training, and as part of my training I have to undertake a research study. I am keen to carry out my research in the field of autism. In particular, I am interested in exploring peoples' experiences of having a child with autism, and what this means for them.

As a parent of a child with autism, I would like to invite you to take part in this research. If you agree to take part you will be asked to meet with me for one interview to discuss your experiences. This interview is likely to last for around 1 hour. At a later date, when I have looked at the information from your interview, I will ask you for some feedback on my findings. This can be done in person or via the mail.

Enclosed with this letter is an information sheet for you to read, which will tell you more about what the research involves. If, after reading the information sheet, you are interested in taking part please tell

, who will then let me know. Please make sure knows what the best way to contact you is (i.e. phone, email, post), and that she has up-to-date details. As soon as I know you would like to take part I will contact you to organise a suitable time and location for us to meet and discuss the research further. If you are still happy to take part we can go ahead and do the interview at this meeting, or, if you prefer we can arrange a second meeting.

Please do not hesitate to contact me if you have any questions or would like to discuss things further before making a decision.

Yours sincerely

Kirsten Jardine
Trainee Clinical Psychologist

Information Sheet

What does it mean to be a parent to a child with autism?

Researcher: Kirsten Jardine

You are being invited to take part in a research study. Before you decide if you would like to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with anyone you choose. Please do not hesitate to contact me or the independent contact if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?

I would like to find out more about your experiences of having a child with autism. To help me do this I would like to meet with you and ask you some questions about your experiences.

Why have I been chosen?

I have asked you to participate because you have a child who has been diagnosed with autism. I am interested in understanding the experiences of parents who have children with this condition.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and do not have to give a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any care or services that you receive.

What will happen if I agree to take part?

If you agree to take part I would like to meet with you to ask you some questions. The meeting will take place either at _____ or at your home, and should last no longer than 1 hour. I will only need to meet you once for the interview. The interview will be recorded so that I can transcribe it later. The recording will be kept in a secure place and when I transcribe it I will ensure that any information that might identify you is removed. The original recording will be destroyed once the research project has been fully written up (approx. September 2008). Once I have analysed your interview and summarised my findings I would like to ask you for

some feedback to make sure that I have accurately understood what you told me. Either we can meet again to discuss this, or you can write feedback down and send it to me.

I will also ask you to complete a short questionnaire to provide me with some background information about your child, such as whether they have brothers and sisters, and what kind of school they go to.

If you would like a summary of the results from the study once it is complete, this can also be arranged.

What are the possible disadvantages of taking part?

Some people can find it upsetting to talk about their experiences.

What are the possible benefits of taking part?

It is not expected that there will be any direct benefits to you of participating in this research, although some people find it helpful to have the opportunity to talk about their experiences. I do hope the study will provide a general benefit to services and parents by continuing our understanding of what it is like to have a child with Autism.

Will my taking part in this study be kept confidential?

All information, which is collected during the course of the research, will be kept strictly confidential. Any information about you, which is used in the final written report, will be made anonymous so that you cannot be recognised from it.

What will happen to the results of the research study?

The findings could potentially be used educate clinicians about what it is like to parent a child with autism. This information could then be passed on to other families whose children are diagnosed with autism. If families know about other parents' experiences they may find it easier to adjust to their own child's diagnosis. The results could also be used to increase social awareness and teach people about what it actually means to be a parent to a child with autism.

Who has reviewed the study?

This research project has been reviewed by the University of Edinburgh, Clinical Psychology Course Organisation Group. It also been approved by NHS Research and Development Department.

Contact for further information

If you would like to talk a bit more about this study before deciding whether to take part, you can contact me (Kirsten Jardine) on [redacted] (Tuesdays 9am-5pm) or [redacted] (Wednesdays & Thursdays 9am-5pm).

Alternatively you might like to email [redacted] If you would prefer to talk to an independent person who is not part of the research team, then you would be very welcome to contact [redacted]

[redacted]. Or you can email [redacted] at [redacted].

If you would like to take part...

If you would like to take part please complete the enclosed sheet with your contact details and give it to [redacted]. She will give it to me so that I know that you are interested. I will then get in touch with you to organise a meeting.

Thank you for taking the time to read this

Contact Details

What does it mean to be a parent to a child with autism?

Researcher: Kirsten Jardine

If you are interested in taking part please complete this slip with your preferred contact details.

Please then give this to _____ who will pass it on to me. I will then contact you to organise a meeting.

Name(s): _____

Telephone No.: _____

Email: _____

Address: _____

Appendix V

Consent Form

Appendix VI

Interview Schedule

Interview Schedule

Guide opening statement

I am interested in finding out more about your experiences of having a child with autism. I have a number of questions to use as a guide to help you think about particular aspects of your experiences.

- *Demographic questionnaire*
 - *Q: How did you come to be here today?*
-

Main Interview Question

- o Tell me about your experience of having a child with autism
-

Prompts

- o How has having a child with autism affected your...
 - Family relationships – marital, siblings, extended family?
 - Social/community involvement?
 - Working life?
 - Self-perceptions?
 - o Can you tell me more about that?
 - o How did that make you feel?
 - o Tell me what were you thinking when...?
-

Back-up questions

- o Can you tell me about some of the contributions that your child has made to the family, friends, and society?
 - o How has having a child with autism affected your/the family's perception of life?
-

Closing question

- o How was the experience for you talking to me today?
- o Is there anything else that you think is important that we haven't talked about?

Appendix VII

Demographic Questionnaire

Background Information

1. Age(s) of parent(s): _____

2. Child's age: _____

3. Age at time of diagnosis: _____

4. School provision: Mainstream Special Educational Needs

5. Has your child been diagnosed with learning disabilities? Yes
No

6. Does your child have any brothers or sisters? Yes No
If Yes, what age(s) are they? _____

7. Who lives in the family home?

(i.e. Mum, Dad, child & sister)

8. Are you the main caregiver? Yes No
If no, who is? _____

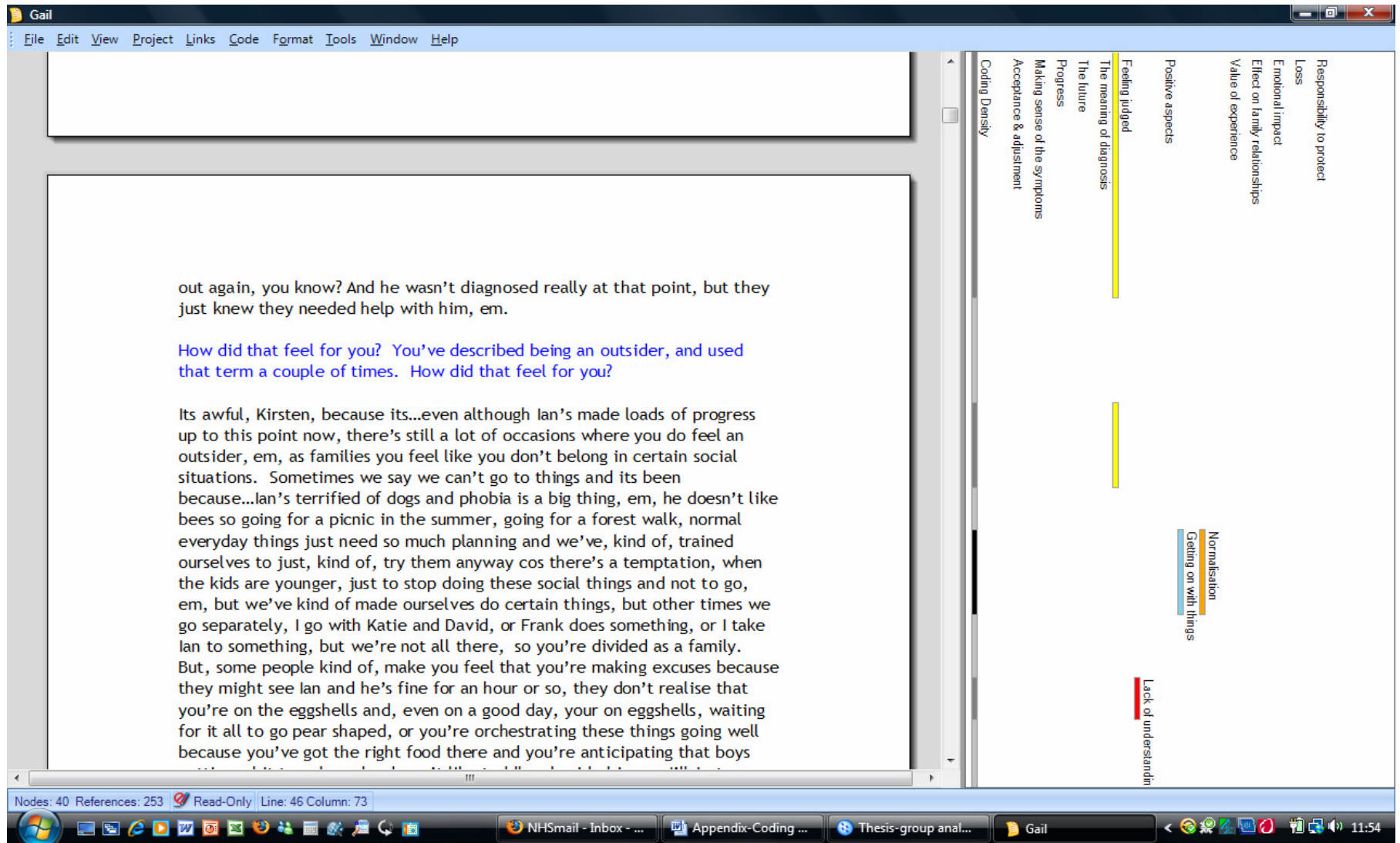
9. Do you work? Yes No
Part-time or full-time? P/T F/T

Appendix VIII

Sample of Coding from Gail's Interview¹⁸

Please note that non-consecutive pages have been used to minimise the likelihood of breaching confidentiality

¹⁸ As noted previously, all names used in this report are pseudonyms.



The screenshot shows a software application window titled "Gail". The main area contains a text document with the following content:

birthday. He can still be anxious and he takes his ear defenders, he's got big huge industrial ear defenders [laugh] and we are trying to get more discreet ones but he doesn't mind wearing them and I don't mind if people stare at us because I think you don't know the achievement for him being here, so I couldn't care if people look at us at the theatre, but no that's what he wants to do, at least they maybe think that he has something he has to wear these for so at least if anything else does happen people can think it must be cos there's something wrong with him, cos he looks just like anybody else, you can't tell that anything is wrong ... and that's the hard thing about Autism as well, because they look like everybody else's boys and girls but in the supermarket at 10 they might throw themselves on the floor you know, or punch their brother or smash things off a shelf and people are kinda tolerant to a point up to about 3 and after that, cos other kids might do that at that age ...and people, you know people can think that but they actually say it sometimes within your earshot and that just amazes me so you have to put up with this, struggling to get your shopping anyway and getting round the store and then a tantrum happens and there's somebody tutting and looking you up and down or something and some days you can just ignore that and other days you can't. I have left trolleys, and left in tears before with Ian and David. I've said to people, you know, my son's actually got Autism, you know do you think you can I have said that to them. Katie's got upset sometimes in restaurants and cafes with people's stares and tutting when Ian has smashed a glass at the garden centre and she's said why do they not know he's got Autism Mum, she was just that little herself and I was they just don't darling and she's said their kids are ugly, you know [laughs] so I've made a wee joke about things like that, you know, but that's been hard for her. She used to feel within herself why don't they know that he's got Autism cos it's just, well it's Ian, it's matter of fact for her and that's difficult as well so it's when you're sorta dealing with a family, trying to help the child's problem it's got this kinda ripple effect, it's sort of everyone around them you know. You're dealing as well with maybe

On the right side of the window, there is a sidebar titled "Coding Density". It contains a list of terms with colored bars indicating their density in the text:

- Responsibility to protect
- Loss
- Emotional impact
- Value of experience
- Normalisation
- Getting on with things
- Positive aspects
- Lack of understanding
- Feeling judged
- Effect on family relationships
- The meaning of diagnosis
- The future
- Progress
- Making sense of the symptoms
- Acceptance & adjustment
- Coding Density

The status bar at the bottom of the window shows: "Nodes: 40 References: 253 Read-Only Line: 46 Column: 73". The taskbar at the bottom of the screen shows several open applications: "NHSmial - Inbox - ...", "Appendix-Coding ...", "Thesis-group anal...", and "Gail". The system clock shows "11:57".

you know, what am I going to do I remember them going away for the weekend and taking Katie away with them and tears just rolling down my face thinking what am I going to do with lan now cos it just, the hours just seemed like they would never end. I tried to go down to the local beach here just for a walk, and I was pregnant with David and lan was just throwing stones into the water, repetitively one after the other and he wasn't diagnosed then but *I knew*, and he wouldn't look at you, his face was just all dour and I just sat and watched him and cried and cried and cried. I just thought I want to sit and tell you about the rocks or think about mermaids and...relationships are such a big part of life you know, and it's just, it's central to things and when you've got Autism and you can't relate it's, it's ... you just feel like....like nothing, it's really hard to put into words, I think if your child can't walk or you know they've got something maybe with their head, hasn't got muscle tone or something but you can still speak to them. If you can have a relationship with them that's the fundamental difference and that's what it's like with Autism because it's built now, we have a good relationship now and lan relates well to his Dad and Frank just adores lan but for a long time that was very fraught and difficult and when that's missing it's just really hard cos you feel so low, you feel very inadequate as a parent, you feel like you're not doing your job well, you feel like you've failed and you just, you can't think what to do. It doesn't matter what you do, it just seems like nothing is going to go right. You look at other people's families and they all seem to be getting on, they are going on holiday or doing normal everyday things and everyday things are just so hard to do, getting through the day is hard to do when it's at that early stage and you have no support. We were lucky in that from quite an early time we did have some respite support through social work but it was, for the first couple of years, not ideal cos people weren't specially trained in Autism and I sometimes went out with this girl who came to be with lan for 2 2½ hour

Responsibility to protect
Loss
Emotional impact
Effect on family relationships
Value of experience
Progress
Acceptance & adjustment

Loss
Emotional impact
Normalisation
Getting on with things
Positive aspects
Lack of understanding
Feeling judged
The meaning of diagnosis
The future
Making sense of the symptoms
Coding Density

File Edit View Project Links Code Format Tools Window Help

Nodes: 40 References: 253 Read-Only Line: 46 Column: 73

NHSmal - Inbox - ... Appendix-Coding ... Thesis-group anal... Gail 11:58

interested in" and she almost gave me permission, I felt, to not manage being this mum that I had in my mind, that I thought you should be with your puzzles and wooden blocks and different things that your child would have. And, after that, I did do that with Ian so, and he liked colours, he seemed to know his colours, so, I bought stickers and books that had shapes and colours and things in them, so if you've got a time where he wanted to do that, he just went with that for that forty minutes, you might get nothing for four days. And he then got to a point where he liked to sing songs, and he'd hide under a blanket and do that, and, he just.....when you did things with him, or he looked at you and smiled or something it was a great feeling cos you felt like you were his mum again and that you weren't just somebody who got a biscuit and juice for him because he only related to me, but that was only as a person who was his needs provider. He didn't

relate to anybody else in the family, that was very hard for Frank, he didn't relate to his dad at all, he didn't really acknowledge his grandparents and he just, kind of, looked through them or his aunties and uncles, and, that was hard for them as well, em, and it's hard for you cos you think your child is rude or something and it's not nice. Now he, he's got to be in the mood for people, but he's so affectionate and knows everybody's name and calls them by name and, he's very much part of the family and so are they to him, you know, his wider circle.

Responsibility to protect
 Emotional impact
 Value of experience
 Normalisation
 Getting on with things
 Positive aspects
 Lack of understanding
 Feeling judged
 The meaning of diagnosis
 The future
 Progress
 Making sense of the symptoms
 Acceptance & adjustment
 Coding Density

Loss
 Effect on family relationships

Nodes: 40 References: 253 Read-Only Line: 1 Column: 65

NHSmail - Inbox - ... Appendix-Coding E... Thesis-group analys... Gail 12:48

the difficulties your child has got. You know they have and I knew he had autism, I felt he did. And for that to be confirmed it was just horrendous, it was awful.

What's going through your mind when this came back and they did the diagnosis?

You're glad in one way, because you feel, "Right, now we can maybe do something about it." I know that's maybe a wee bit naive as that's just the start of your problems really, but, at the time you sort of think "Right, now that we know, okay, we've got to go on and do it". But I'd sort of known they were going to say that anyway because the first couple of days I met the clinical psychologist, who's also retired and was also S, and she said to me "what do you think it is?" and I said "I think he has autism" and she couldn't officially confirm it, because they're not allowed to, but, she said "You're probably right" or words to that effect. And I just felt a sense of relief as I thought I could speak to her, I thought "Right! You are going to listen to me" because my husband had been "Don't be stupid" and in denial about it because, obviously he didn't want to face that cos it's a big thing to face. So he wasn't, and my mum wasn't really, and I felt really alone with it and, for her to say "Yes, he does behave like certain children" I just felt I could speak to her and ask her lots of questions. And she was quite happy to let Ian, cos she was obviously watching him too, potter about and he was more relaxed there cos there wasn't expectations on him, she just wanted to see what he could and couldn't do, and all the time she was chatting to me. So I felt that she'd listened to me, and that afternoon the educational psychologist came to visit, and, the nursing staff were there and they were asking me to, I think they were watching how I was interacting with him or they wanted me to do things that Ian was comfortable with, so it wasn't with a stranger. And he just had an hour and a half they saw my little boy as he could be, and I just thought "If you don't do anything else this week, if

Responsibility to protect
Loss
Emotional impact
Effect on family relationships
Value of experience
Normalisation
Getting on with things
Feeling judged
The meaning of diagnosis
The future
Progress
Making sense of the symptoms
Acceptance & adjustment
Coding Density

Lack of understanding

Positive aspects

Nodes: 40 References: 253 Read-Only Line: 1 Column: 65

NHSmail - Inbox - ... Appendix-Coding E... Thesis-group analys... Gail 12:49

that and that but no, come on, I'm wanting them to help me, what else can you tell me, show me, help me learn about, and actually maybe there wasn't any more sometimes and you would feel a little bit ooh. Like dieticians I found that with, they didn't know as much as I did because I had gone into it in a lot of detail. They are dealing with dietary things on a massive range, not just kids with Autism, but that's what I homed in on, I went expecting more but I thought oh I'm educating you, oh right, oh no, who can I ask, I need somebody to ask now cos that wasn't helpful cos they were dismissive of certain I thought you don't know cos you haven't looked into that, if you know, fine, let's have a discussion but if you don't, don't rubbish what I'm saying. Just because you haven't come across it doesn't mean that it isn't right. So you get that kind of thing, so people need, or they *should* know that people come with different experiences and different backgrounds and ask them, you know, if you're not sure say...what do you know or what would you like me to speak about or how can I help you or whatever it is. Different people can take on different amounts at different times. And when you're grieving, you're dealing with so many emotions because you just, you do, you have to go through that process. You've lost the child you think that was born to you because it's not like Down's Syndrome where you can see as soon as they are born, you don't know when your child is born that they have got Autism so your mind is thinking of, you know, of brothers and sisters playing together, of going to school, of getting married or whatever and when you are given this news, you've then got to come to terms with what does this mean, you know, will he be like this for the rest of his life cos you just don't know and once you go to BBBB you see a whole range of kids there and there are some kids that are older than the boys you see that have left it's very much

Coding Density

- Responsibility to protect
- Loss
- Emotional impact
- Effect on family relationships
- Value of experience
- Normalisation
- Getting on with things
- Positive aspects
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- Progress
- Making sense of the symptoms

- Lack of understanding
- The meaning of diagnosis
- Acceptance & adjustment

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Appendix IX

Summary of Main Themes from Integrated Analysis

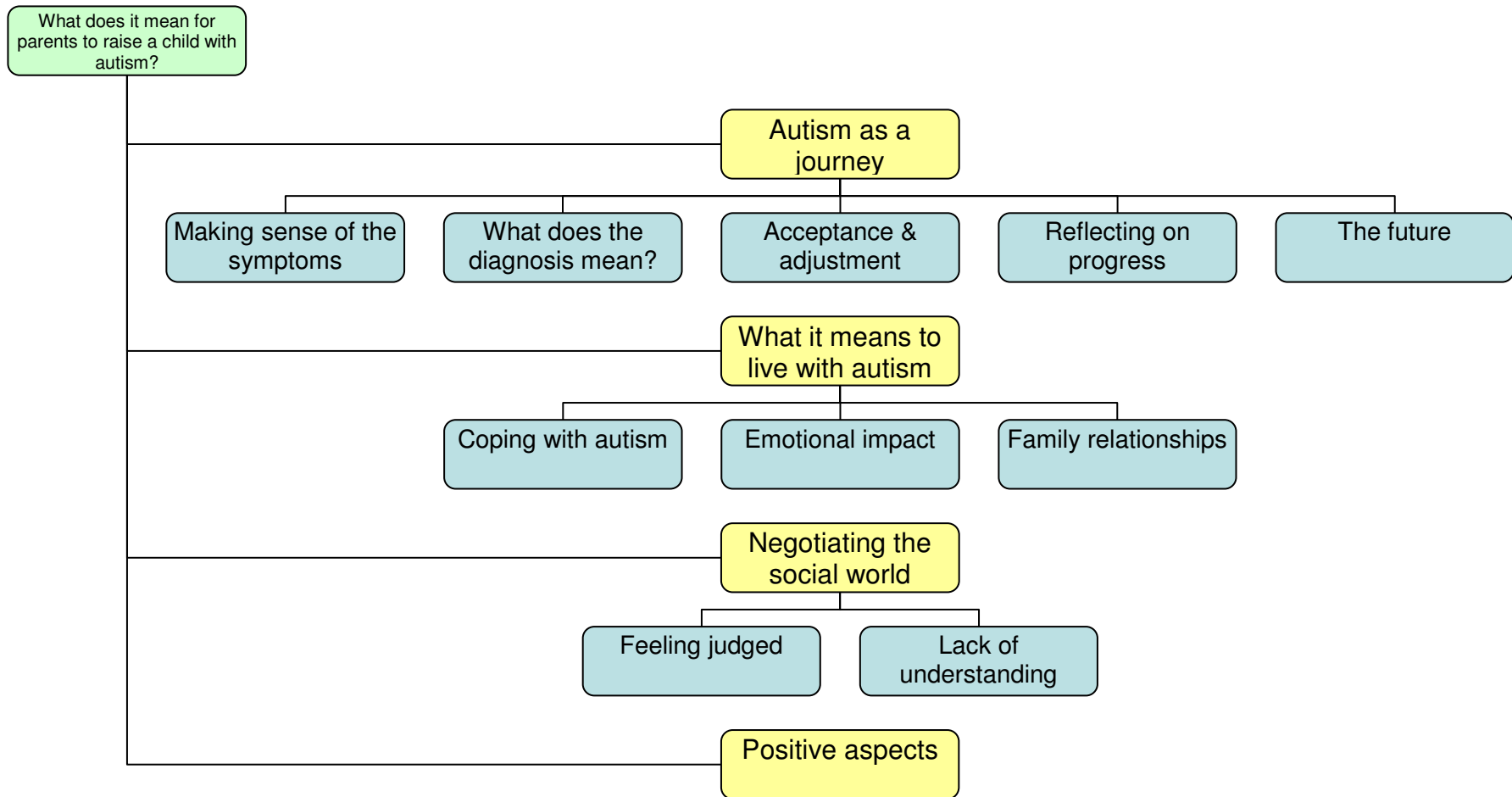


Figure 4. Summary of main themes from integrated analysis

Appendix X

Summary of Themes Identified for Individual Participants

Anna & Paul¹⁹

Gail

Jane

Jenny

John

Mandy

Sarah & Alan

¹⁹ As noted previously, all names used in this report are pseudonyms.

Themes of Anna & Paul's Experiences

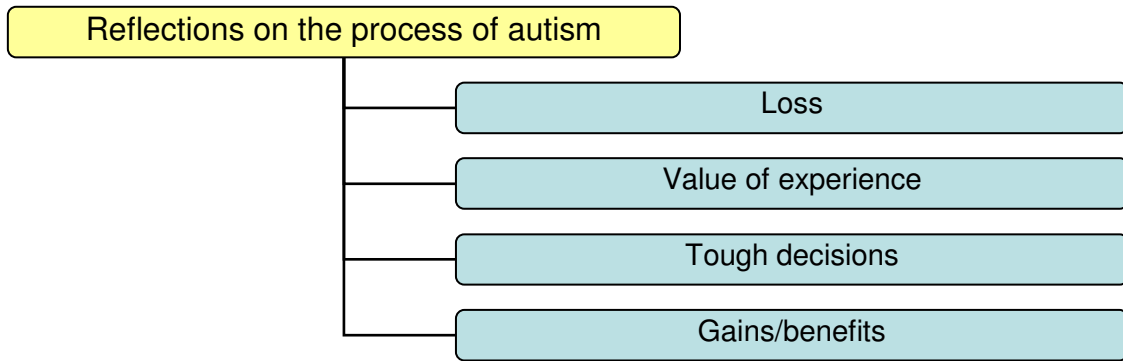


Figure 5. Core theme *Reflections on the process of autism* and related sub-themes

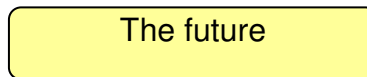


Figure 6. Core theme *The future*

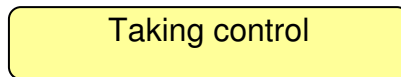


Figure 7. Core theme *Taking control*

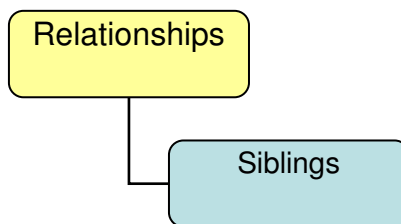


Figure 8. Core theme *Relationships* and related sub-theme

Themes of Gail's Experiences

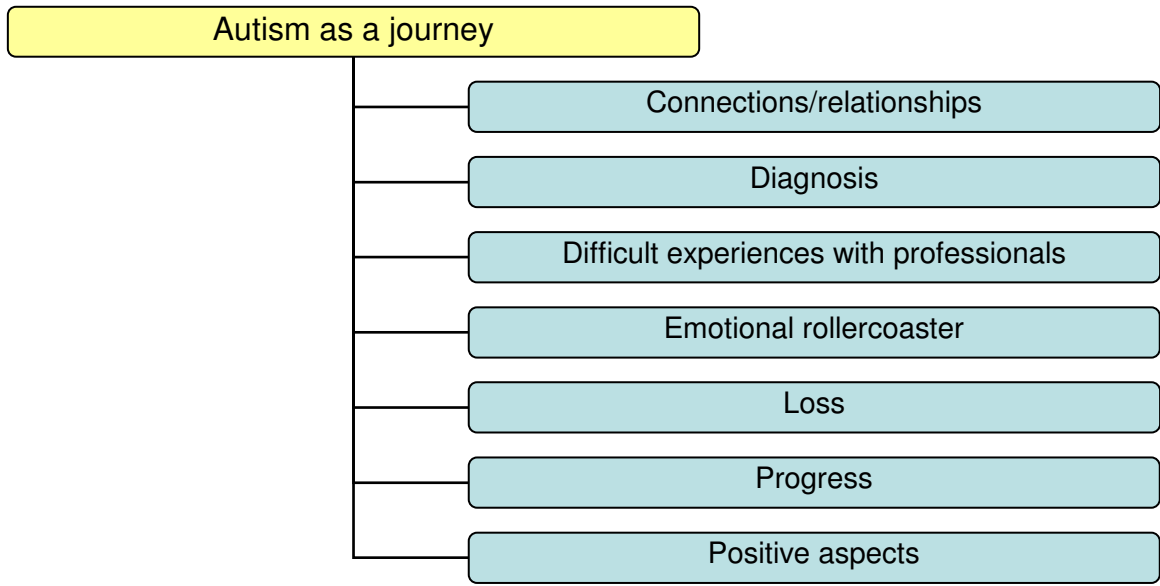


Figure 9. Core theme *Autism as a journey* and related sub-themes

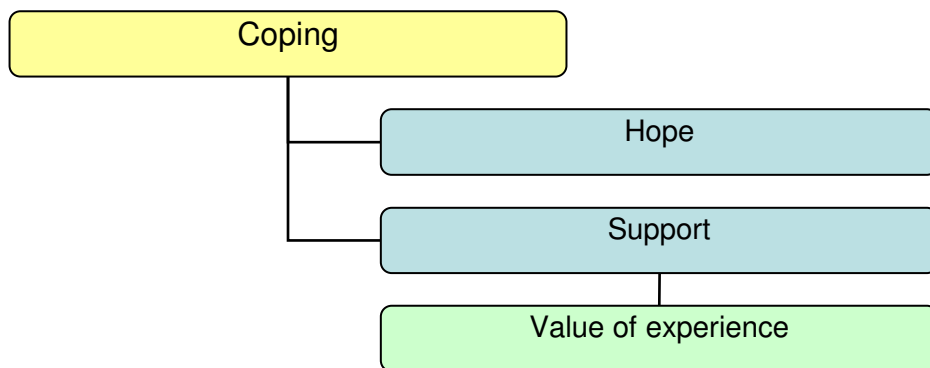


Figure 10. Core theme *Coping* and related sub-themes

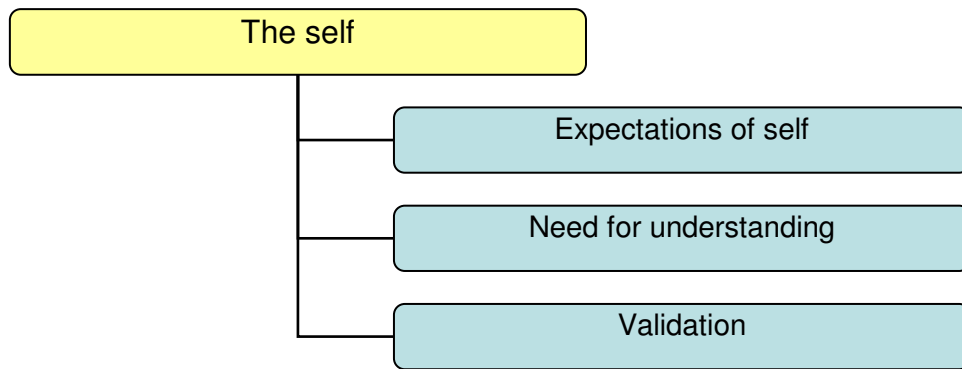


Figure 11. Core theme *The self* and related sub-themes

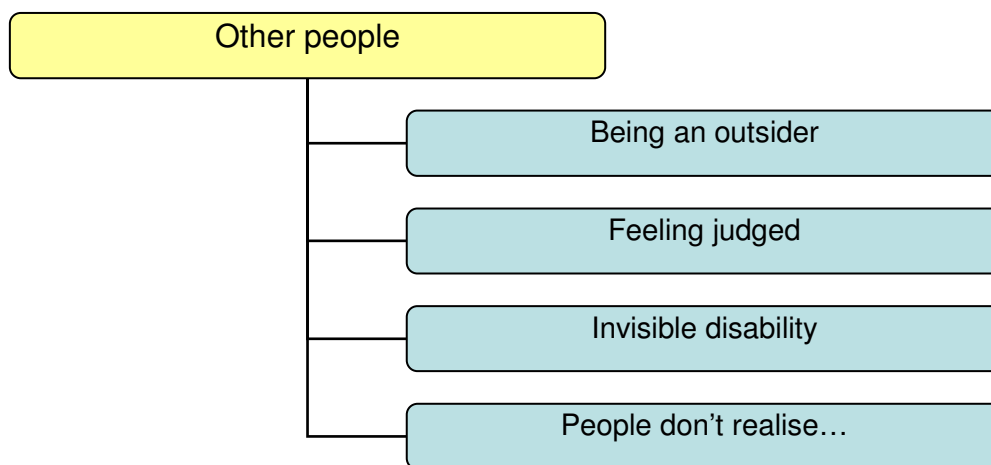


Figure 12. Core theme *Other people* and related sub-themes

Themes of Jane's Experiences

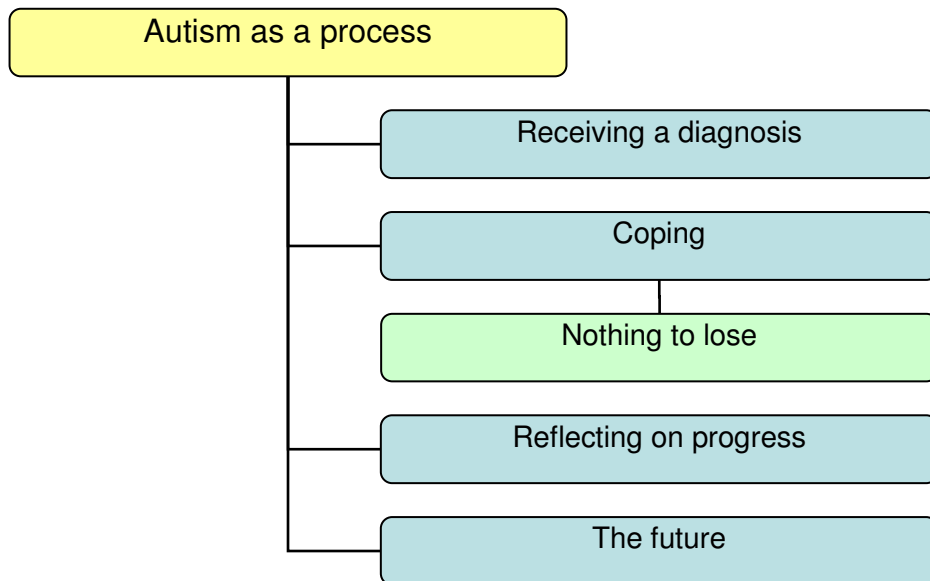


Figure 13. Core theme *Autism as a process* and related sub-themes

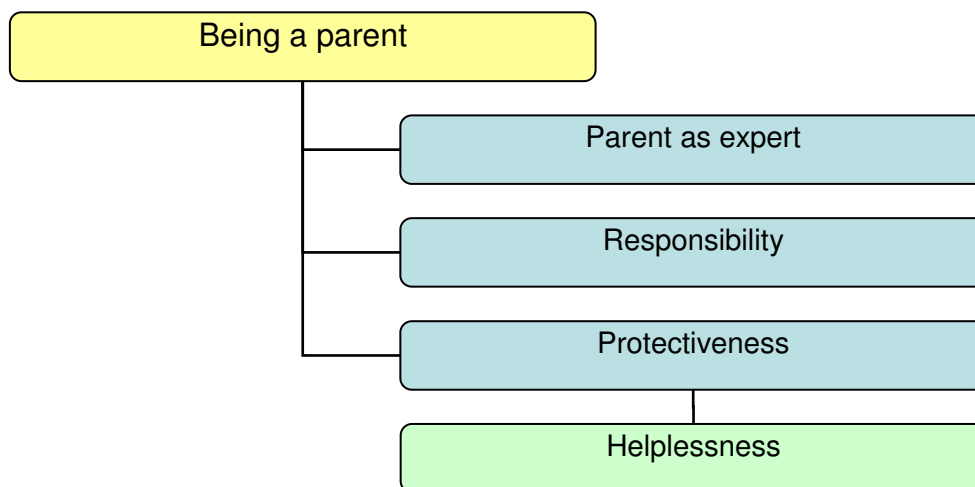


Figure 14. Core theme *Being a parent* and related sub-themes

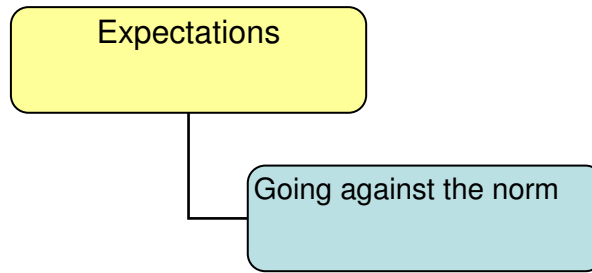


Figure 15. Core theme *Expectations* and related sub-theme

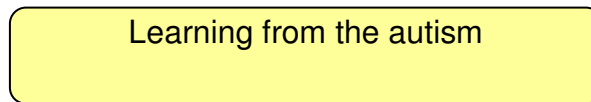


Figure 16. Core theme *Learning from the autism*

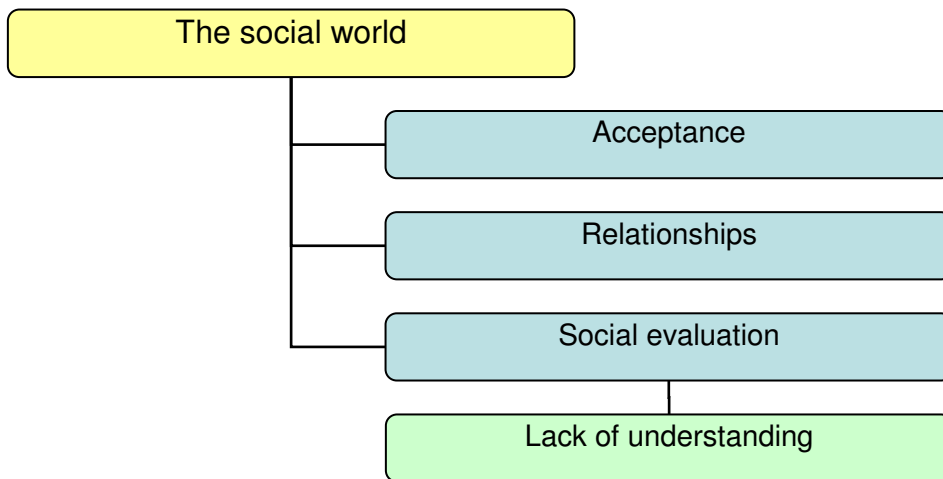


Figure 17. Core theme *The Social World* and related sub-themes

Themes of Jenny's Experiences

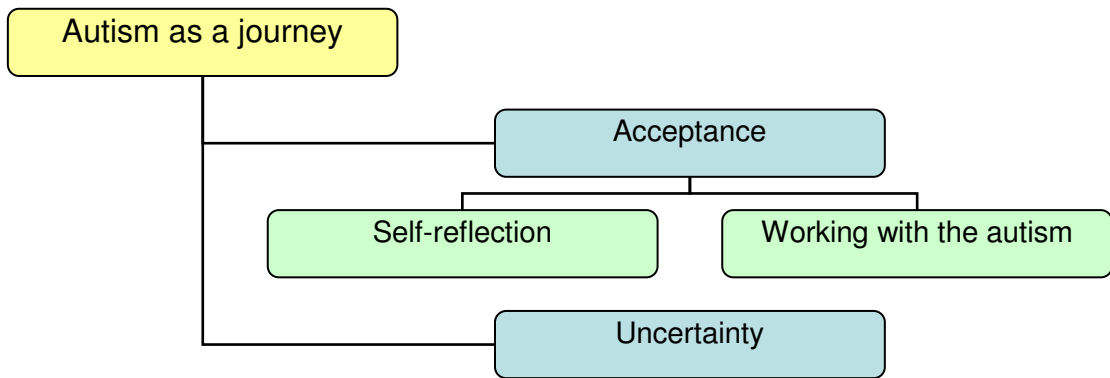


Figure 18. Core theme *Autism as a journey* and related sub-themes

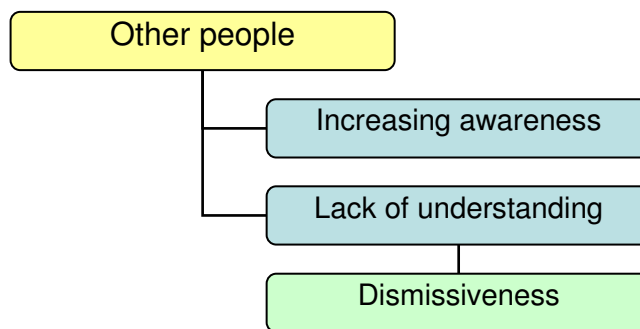


Figure 19. Core theme *Other people* and related sub-themes

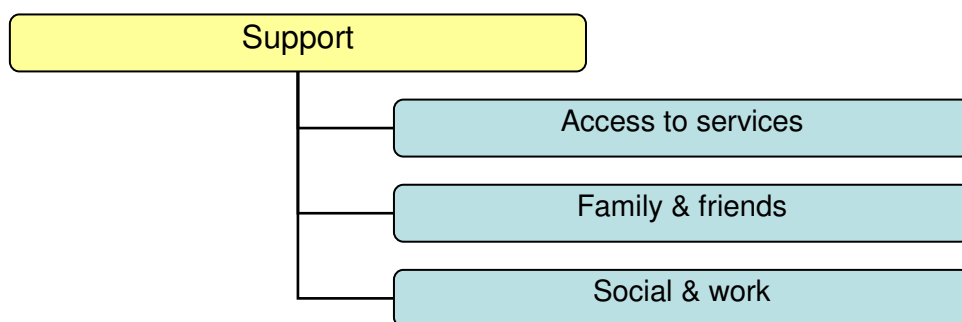


Figure 20. Core theme *Support* and related sub-themes

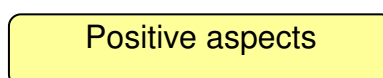


Figure 21. Core theme *Positive aspects*

Themes of John's Experiences

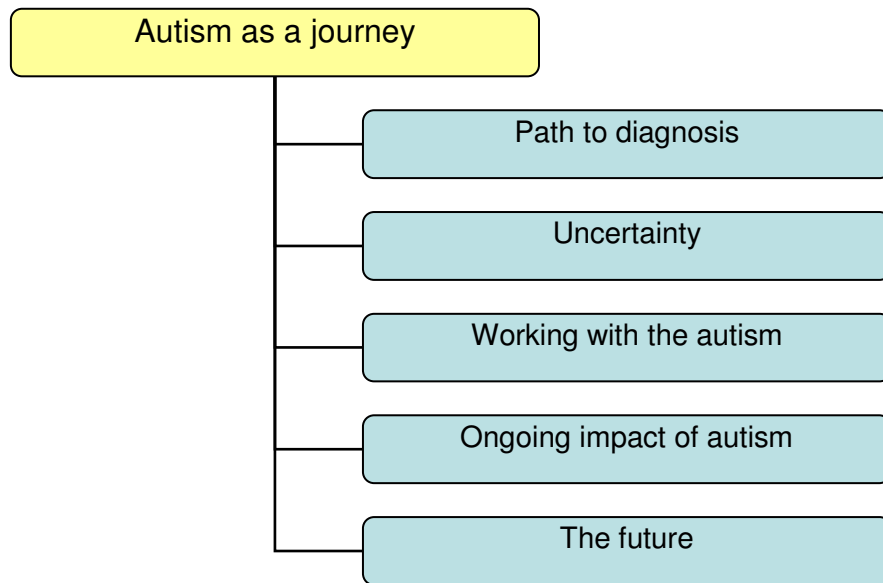


Figure 22. Core theme *Autism as a journey* and related sub-themes

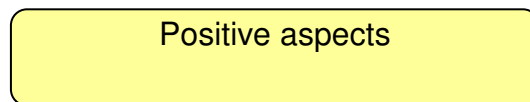


Figure 23. Core theme *Positive aspects*

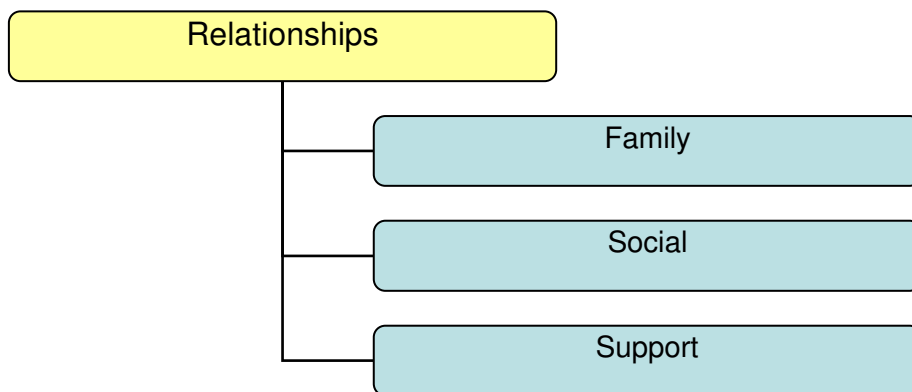


Figure 24. Core theme *Relationships* and related sub-themes

Themes of Mandy's Experiences

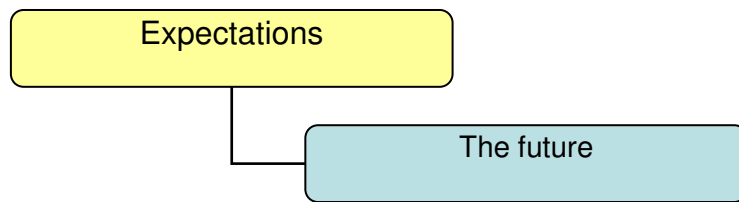


Figure 25. Core theme *Expectations* and related sub-theme

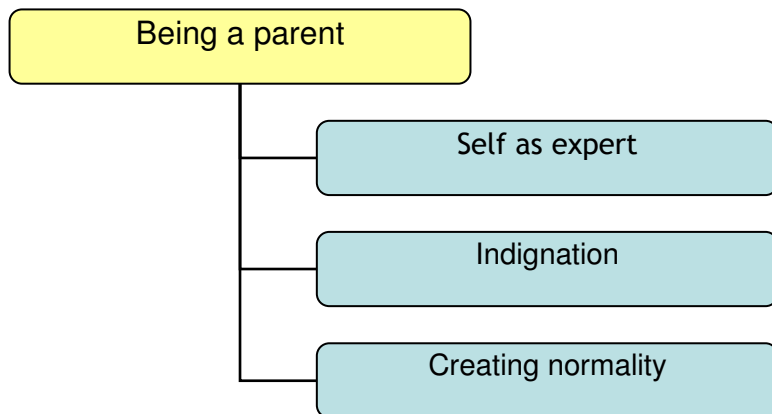


Figure 26. Core theme *Being a parent* and related sub-themes

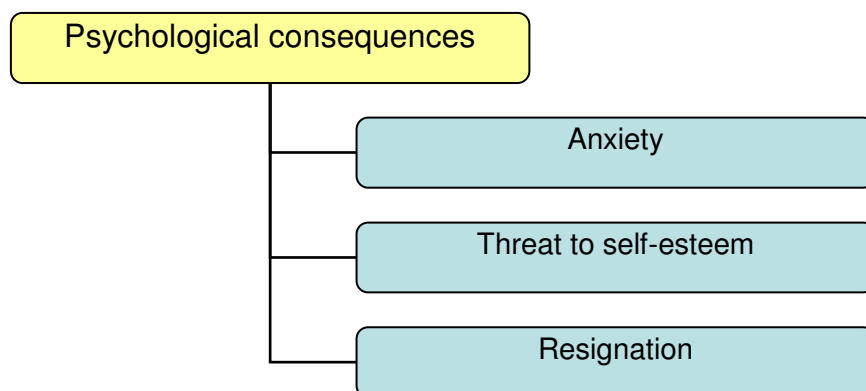


Figure 27. Core theme *Psychological consequences* and related sub-themes

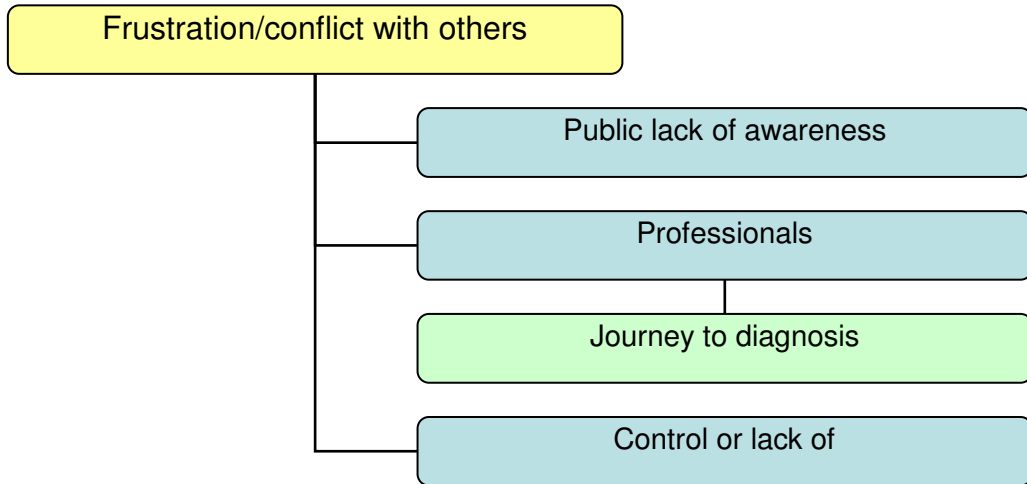


Figure 28. Core theme *Frustration/conflict with others* and related sub-themes

Themes of Sarah & Alan's Experiences

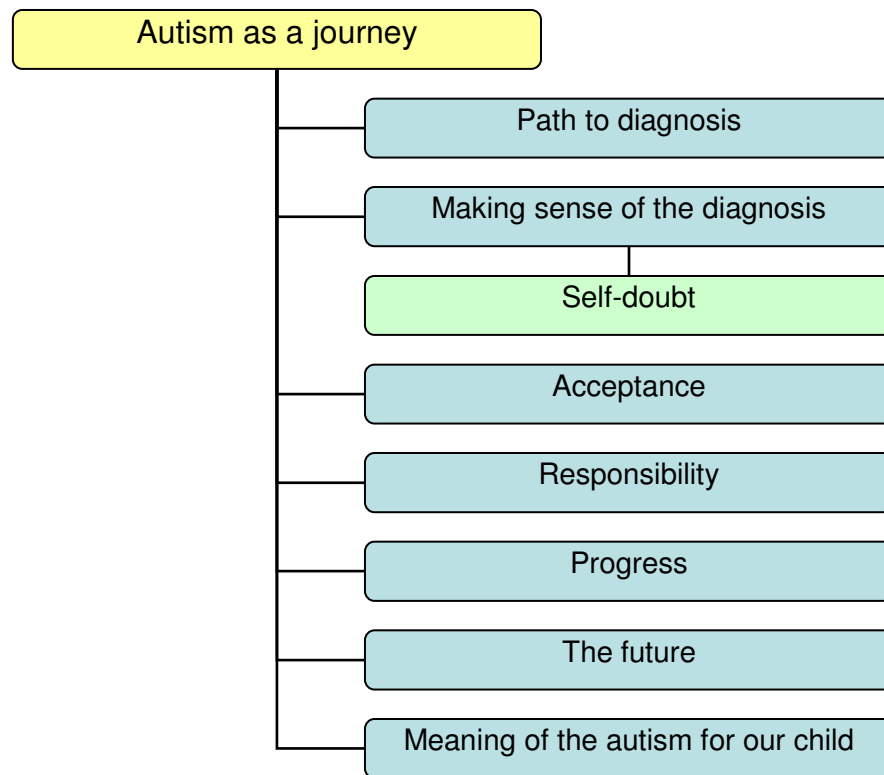


Figure 29. Core theme *Autism as a journey* and related sub-themes

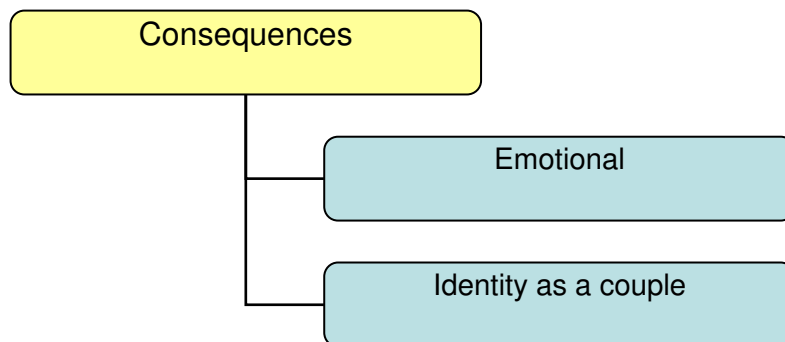


Figure 30. Core theme *Consequences* and related sub-themes

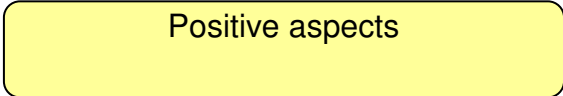


Figure 31. Core theme *Positive aspects*

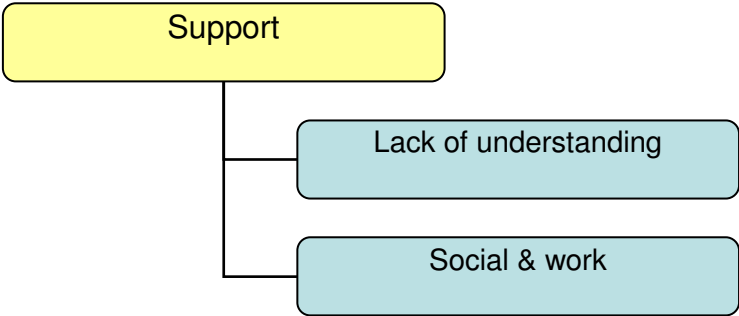


Figure 32. Core theme *Support* and related sub-themes