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Navigating Neurodiversity
-the experiences of neurodiverse people and the people who support them.

David Berry

THE UNIVERSITY
of EDINBURGH

Doctorate in Clinical Psychology
The University of Edinburgh
Submitted in 2022

Submitted in partial fulfilment of the degree of doctorate in Clinical Psychology at the University of Edinburgh

Word Count (excluding references and appendices): 18708
This work is dedicated to my family, My Mother, Father and Sister, who have always supported me throughout my life and through this degree. I would not be the man I am today without you. I love you to the moon and back.
Acknowledgements

This experience, of completing the Doctorate in Clinical Psychology has truly been one of the most challenging and rewarding experiences of my life. I would not have reached the end if it wasn’t for all the help and support I received from so many people across Scotland, Ireland and beyond. Firstly I would like to express my deepest gratitude to the participants and other researchers across the UK who have made this project possible.

I cannot express in words how grateful I am to my Academic and Clinical Supervisors, Dr Karri Gillespie-Smith and Dr Katrina Johnston. Without their unwavering support throughout the programme I would never have been able to produce this work and become a Clinical Psychologist. Thank you both for believing in me. Thanks as well to my mentor, Dr. Clare Brady.

Thank you to Lauren Gillies-Walker for working on this project alongside me. Thanks also to Janie Laughlin and Dr. Carrie Ballantyne for collecting the data used in this project.

Thanks to my friends and colleagues and fellow trainees. Especially to Orlagh, Sarah, Corinna, and Miriam, who were so supportive when I lived in Edinburgh. Also to Michelle and Oisín for being loyal friends.

Lastly I would like to acknowledge my Mother, Sister and Father for everything they have done to keep me well, for all their support and all their love, without which this work would have been impossible.
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Thesis Abstract

The neurodiversity movement has gained momentum in the last number of years with many neurodevelopmental conditions now being part of a person’s identity and not just medical disorders. With this, more researchers have become interested in the experiences of neurodiverse people as well as their families and carers. However, some people have remained neglected in the literature including autistic women and the siblings of people with disabilities. We conducted a systematic review into the experiences of siblings of people with learning disabilities and a novel qualitative study focusing on the experiences of autistic women and mothers of autistic daughters going through the diagnostic process. Several themes were elicited and discussed, giving voice to these often overlooked groups. Results show that the siblings and women engaging in the diagnostic process for autism had unique experiences and these people’s perspectives offer an interesting insight into how neurodiverse people can be supported. Implications for future research and practice are discussed.

Lay Summary

Neurodevelopmental disorders such as autism and learning disabilities are no longer considered to only be disabilities, but are often viewed as part of a person’s identity. People with these conditions are considered neurodiverse. Researchers want to learn more about people with these different conditions, as well as their carers. A lot research has been done on men with autism and parent carers of neurodiverse people. Not as much information is available on women with autism and other types of carers including siblings. We did two studies where we looked at the opinions and experiences of autistic women and siblings of people with Learning Disabilities. This allowed us to learn more about these groups and we found several themes in what they have to say. These people had unique experiences which adds to our knowledge about neurodiversity. This research will help researchers and clinicians in the future.
Chapter 1: Systematic Review

“It isn’t a burden, it’s just a weight I carry”- A systematic review and meta-synthesis comparing the experiences of child and adult siblings of people with a learning disability

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\textsuperscript{c} NHS Fife Psychology Department, Lynebank Hospital, Dunfermline, Fife, UK

Written according to the submission guidelines for the Journal of Autism and Developmental Disorders (See Appendix A)

Word Count (Excluding references and appendices) 9395
Abstract
Learning Disability is a lifelong neurodevelopmental condition typified by deficits in intellectual ability denoted by an IQ below 70, and deficits in adaptive functioning, with an onset in childhood. People with Learning Disabilities are likely to need support with activities of daily living throughout their lives. Their siblings are often lifelong carers and supporters of these people. Despite this, siblings are often neglected in research and services. This systematic review and meta-analysis reviewed 20 qualitative papers on the experiences of siblings of people with disabilities. Superordinate themes elicited included Daily Life, Coping, A Lifelong Commitment?, Shifting Systems and Positive and Negatives. Implications for future research and clinicians are discussed.

Keywords: Intellectual Disability, Learning Disability, Siblings, Experiences, Systems
**Introduction**

Learning disability (LD) or intellectual disability (ID) is a neurodevelopmental disorder characterised by deficits in intellectual ability denoted by an IQ (Intelligence Quotient) below 70, and deficits in adaptive functioning, with an onset in childhood (American Psychiatric Association, 2013; World Health Organization, 2020). Tassé et al., (2016) suggest these components of ID have remained constant over the last 50 years, especially in the USA. Over time more weight has been given to the behaviour component and the newest Diagnostic Statistical Manual (DSM 5), published in 2013, requires an equally rigorous examination of adaptive behaviour and intellectual functioning. “Adaptive functioning” is behaviour which is “the collection of conceptual, social, and practical skills that have been learned by people in order to function in everyday lives” (Luckasson, et al., 2002).

ID is considered a *syndrome grouping* or cluster of symptoms which can have a range of causes including genetic, nutritional, metabolic, infectious, neurotoxic or physical/injurious causes. (Salvador-Carulla & Bertelli, 2008). The disability is often comorbid with other difficulties including mental health, neurodevelopmental, neurological and medical problems. The deficit in intellectual functioning may cause a range of difficulties in different cognitive skills including logical reasoning, problem solving, learning ability, verbal and visuo-spatial skills, and speed of processing information. Deficits in adaptive behaviour denote difficulties in social (choosing and making friends), conceptual (communication, functional academics such as understanding a bill, and self-direction) and practical skills (community use, health and safety and self-care skills) (Lee et al., 2019). As a result of these difficulties, people with intellectual disabilities are likely to require extra support throughout their lives.
Challenging behaviour (CB) can be defined as

“Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.” (Royal College of Psychiatrists, 2007)

While CB may be very difficult for those around the disabled person, it may be adaptive for the person. Therefore CB may be caused by frustration in the environment, which may require adjustment (Tanwar, et al., 2015). Prevalence of CB can vary in different environments. For example Oliver et al., (1987) found that rates of (self-injurious) CB varied from 12% in hospitals to 3% in the community, whereas Borthwick & Duffy (1994) found a difference of 49% in institutions to 3% in the community. This may be because of the stressful and strange nature of the institutions compared with homes, but also due to discrepancies and biases in reporting, i.e. high burden may make professional staff report CB more. Overall 5-15% of people with learning disability known to services will present with CB (Tanwar et al., 2015). Presence of behavioural, affective and psychotic disorders and disabilities which inhibit self-care and social inclusion are more likely to heighten family burden (Irazabal et al., 2012).

Children (or siblings) with learning disability (CWD or SWD) have a number of effects on families, but research focuses on their parents rather than siblings (Begum & Blacher, 2011; Tomeny et al. 2017; Davys et al. 2011). Emerson and Giallo (2014) found that children with long-term health conditions and disabilities, including LD, are more likely to live in low socio-economic areas, with their families experiencing financial hardship. More specifically Okoli et al., (2022) found that CWD were more likely to be born into families with food poverty, health poverty and financial poverty, as those families were more likely to have disabled children due to
inequalities in healthcare and nutrition. This may influence the factors which cause LD as explained already above.

Parents of CWD are more likely to experience higher levels of stress than those of typically developing children (TDC) (Dyson, 1993; Dyson, 1997; Rodrigue et al. 1990; Roach et al. 1999; Hassall et al. 2005). Hassall et al, maternal stress may be attributed to differences in maternal locus of control, parenting satisfaction and child behaviours. CBs contributed significantly to maternal stress. Familial support correlates negatively with parental stress, but this is mediated by parental locus of control (Hassall et al., 2005). Gillespie Smith et al., (2021) also note that CBs negatively affect carers’ mental health. Distress was moderated by carers’ coping mechanisms. Avoidant coping strategies such as denial and disengagement had a negative impact on carers’ stress levels.

Typically developing siblings (TBS) may also encounter challenges that their peers may not, and report more negative life events and inconsistent parenting than their peers (Dyson, 2010). Findler and Vardi (2009) demonstrate positive outcomes for siblings, however these mostly focus on personal growth, such as greater resilience. Other positives included the swld being a source of joy, having a purpose due to having extra responsibilities, expanded personal and social networks, increased spirituality, family closeness and increased tolerance, empathy and understanding (Stainton & Besser, 2009).

Relationships between SWLD and TDS may differ, especially when there is CB (Begum & Blacher, 2011; Neece et al. 2010) and TDS may be less warm towards more disabled SWLD (Doody et. Al, 2010). The addition of Autism Spectrum Disorder (ASD), may result in worse sibling relationship attitudes. This is important because TDS with positive attitudes are more likely to support SWLD, have greater life satisfaction, lower stress and are less likely to be
depressed (Doody et. Al, 2010; Tomeny et al., 2017). Again CB and communication problems may negatively impact relationships (Tomeny et al. 2017). Dubnow (2017), and Tozer & Atkin (2015) express more mixed outcomes, highlighting personal growth noting personal growth and issues with CB, although TDS did want a role in the SWLD’s lives.

Hames et al. (2008) found in their 12-year longitudinal study, studying TDSs from about 2-14 years of age, that children can conceptualise LD from a young age and that this develops throughout childhood. Stalker and Connors (2004) interviewed 6-19 year old siblings and also found strong understandings of LD from early childhood. Participants copied SWLD early on but copied the parents later, helping with caring activities. Differences became greater as the TDC develops. Despite these differences, some siblings are emphasised the similarities between their families and their peers, emphasising their lives were “normal” (Stalker and Connors, 2004).

Sibling relationships develop into adulthood and are often life-long. Davys et al. (2011) conducted a literature review on the experiences of adult siblings. Key themes related to life choices, relationships, identity and future plans. Again outcomes were mixed with positive family and sibling closeness, and the negative impact of caring responsibilities, future worries and stress. Again, they often expressed a kind of “normality”; however, this was variable and dependent on key factors such as gender, life stage and circumstances, level of disability, health status and relationships between family members (Davys et al., 2011). It is suggested life stage especially affects caregiving duties. Parents often care for disabled siblings as children, TDSs adopt this role when parents become too old (Davys et al., 2011). Having a disabled child could affect parenting style and attachment with other siblings which may lead to negative outcomes later on. Parents often need to spend more attention on the SWLD therefore TD siblings may feel neglected. In addition, added responsibility may make TDSs feel parentified (Coldwell, Pike &
Dunn, 2008). It is clear therefore that sibling roles change throughout life, but this has not been formally reviewed in the literature.

Despite the clear importance of the sibling relationship in supporting people with LDs there is a lack of research and systematic reviews on the topic. Vo et al. (2018) published a review on DiGeorge Syndrome, which frequently causes intellectual disability alongside various physical disabilities. The researchers found that child TDSs expressed frustration due to not having parents’ attention. This caused jealousy of their siblings which led to shame and guilt. Children knowledgeable about the disability and were aware of their possible future care roles. The responsibility caused a sense of sadness but also pride in the TDC. Tudor and Lemer (2015) reviewed support groups for child siblings and their effects. They found that children who accessed support groups for siblings of people with developmental disabilities (DD) exhibited changes in their perceived social support, self-esteem, knowledge about disability, and emotional and behavioural adjustment, and groups were also enjoyable. Changes in sibling relationships were mixed across these papers, with only some reporting less sibling stress following support. Results on changes in negative attitudes were also mixed (Tudor & Lemer 2015). Many of the reviewed articles featured small sample sizes and several took an explorative rather than an experimental approach, where control groups or test re-test approaches were not used.

Child TDS acknowledge how stigma against their sibling has a negative impact on the SWLD, their families and themselves, according to one review (Ali et al., 2012) Stigma negatively impacted their mental health and how they and the SWLD were treated. Mitter, Ali and Scior (2019) found that adult carers, including grandparents and siblings, can experience stigma as a result of having a disabled child. Stigma can affect various family members but this is often overlooked in research. Lobato (1983) emphasised that outcomes need not necessarily be
negative. However sex and birth order may affect roles, as the first-born female is often given the most responsibility, and older siblings have more responsibility than young ones (Lobato, 1983). Lee and Burke (2018) studied adult caregiving. Adult TDSs expressed mixed outcomes regarding caring for a sibling with LD or Developmental Disability (DD). Innes, McCabe and Watchmen (2012) interestingly found that, even older people with LD may be solely supported by elderly parents. This suggests that while adult siblings’ experiences of their role can vary, many siblings will see a change in later life due to parental illness, infirmity or death.

TDSs of people with LD may have unique experiences of the sibling relationship. This relationship may evolve over time due to changing care roles. To date, no systematic review has been carried out comparing the experiences of child versus adult siblings of people with LD instead focusing on children or adults. Therefore, the current review will seek to address the research question; How is the sibling relationship experienced in child and adult siblings of people with Intellectual Disabilities?

**Method**

**Inclusion/Exclusion or Eligibility Criteria**

The focus of this meta-synthesis will be to compare experiences of child and adult siblings of people with LD. Only explorative and qualitative studies were used, using methods such as interpretative phenomenological analysis (IPA), thematic analysis (TA), grounded theory (GT) etc. Studies including children (under 18 years) and adults (18 and above) were included and analysed. Only studies including the siblings themselves were to be used, i.e. papers that included only other family members’ views on sibling relationships were not included. Mixed participant populations (for example including parents and siblings) were used if the origins of contributions were clear. Papers were included from a 42 year period from 1980 to April 2022.
This coincides with the publication of the DSM-III (1980), which introduced more explicit diagnostic criteria, and a more neutral approach to the aetiology of mental disorders. There was more of an emphasis on adaptive functioning in the DSM-III, in keeping with a modern understanding of intellectual disability (Spitzer and Cantwell, 1980). Thus papers published after 1980 may be more reliable and neutral in approach.

Our criteria were therefore as follows:

Papers had to be:

- Published since 1980
- Using qualitative methodology
- Including adult and/or child siblings of a person with LD (for simplicity, studies including any LD were included, and those that had autism were also included).
- Written in the English language
- Primary empirical studies, not case studies, meta-analyses or reviews themselves

**Information sources and search strategy**

The search strategy was devised between the authors and a University of Edinburgh librarian. We searched Apa Psycarticles, Embase, Ovid Medline, Apa Psycinfo, Applied Social Science Index and Abstracts and Sociological Abstracts databases. In order to include grey literature, theses and dissertations, we also searched the Proquest Dissertations and Theses Global database. This allowed for data which might not be available in peer reviewed journals to be included.

Search terms included:

intellectual* disab* OR intellectual development disorder OR Learning disab* AND Sibling* OR brother* OR sister* AND Experience* OR attitude* This search returned a total of 1099 papers. Our inclusion/exclusion criteria were then applied to each paper in turn.
Selection process and data extraction

Once searches were conducted, the associated RIS files were uploaded to Covidence Data Management Software to perform exclusion and data extraction. We used the Preferred Reporting Items for Systematic Reviews (Prisma) protocol (Moher et al., 2009). 1099 records were added to covidence and 154 records were removed after deduplication leaving 945 records. Titles, abstracts and (if required) full texts were appraised for inclusion criteria, eliminating 879 and leaving 66 papers for full text review. This left 20 papers for extraction. 6 of these (30%), were reviewed by a second rater for inclusion and there was 100% agreement. This process is outline in Figure 1. Descriptive information was extracted from each of the 20 papers and included in table 1. Two papers, (Atkin 2014; 2015) may have drawn from the same sample but had different focuses and aims, so both papers were included.
Figure 1.

*Prisma Flow Diagram (Page et al., 2021)*

![Flow Diagram](image)

- **Identification**
  - Records identified from*: Databases (n = 1099)
  - Records removed before screening: Duplicate records removed (n = 154)

- **Screening/Eligibility**
  - Records screened for title and abstract (n = 945)
  - Records excluded**: (n = 879)

- **Inclusion**
  - Records assessed for eligibility (n = 66)
  - Reports excluded (n = 46): Wrong study design (n = 18), Wrong disabled population (n = 9), Outcome sources unclear (n = 7), Wrong interviewee population (n = 7), Wrong Outcomes (n = 4), Wrong Language (n = 1)
  - Studies included in review (n = 20)
Table 1.

**Descriptive Data Table**

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Title</th>
<th>Aim</th>
<th>Participants (N, gender, ages, ethnicity/nationality)</th>
<th>Sibling Disability</th>
<th>Age Group</th>
<th>Setting</th>
<th>Data collection and analysis</th>
<th>Analysis</th>
<th>Main Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atkin, 2014*</td>
<td>&quot;Personalisation, family relationships and autism: Conceptualising the role of adult siblings&quot;</td>
<td>explored siblings’ perspectives on having a brother or sister with autism</td>
<td>21, 14 female, 25-67, Uk English</td>
<td>ASD and Learning Disability</td>
<td>Adult</td>
<td>University, Peer reviewed</td>
<td>Semi-Structured Interview</td>
<td>Thematic Analysis</td>
<td>1 sibling relationships 2 expectations of social care and personalisation</td>
</tr>
<tr>
<td>Atkin, 2015*</td>
<td>&quot;Recognized, Valued and Supported&quot;? The Experiences of Adult Siblings of People with Autism Plus Learning Disability</td>
<td>Explore expectations of social work with adult siblings</td>
<td>21, 14 female, 25-67, Uk English</td>
<td>ASD and Learning Disability</td>
<td>Adult</td>
<td>University, Peer reviewed</td>
<td>Semi-Structured Interview</td>
<td>Thematic Analysis</td>
<td>1 past relationships, 2 current relationships, 3 caring relationships, 4 experiences of service provision</td>
</tr>
<tr>
<td>Avieli, 2019,</td>
<td>How Middle-Aged Siblings of Adults with Intellectual Disability Experience their Roles: a Qualitative Analysis</td>
<td>&quot;explore the ways middle aged typical siblings shape and perceive their role within the aging family.&quot;</td>
<td>17, 10 Female, 45-65</td>
<td>Intellectual Disability</td>
<td>Adult</td>
<td>University, Peer reviewed</td>
<td>Semi-Structured Interview</td>
<td>IPA</td>
<td>(1) Sibling multiple roles along the life course; (2) The sibling’s role in the changing alignment of aging families living with disabilities; (3) A retro- spective examination of</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Methodology</td>
<td>Data</td>
<td>Findings</td>
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<tr>
<td>Benderix 2007</td>
<td>Siblings' Experiences of Having a Brother or Sister With Autism and Mental Retardation: A Case Study of 14 Siblings From Five Families</td>
<td>Collecting data through semi-structured interviews and content analysis</td>
<td>14, 6 female, 5-29, Swedish, ASD and Mental Retardation, Both University, Municipal Centre, Peer reviewed</td>
<td>1) Precocious responsibility; 2) Feeling sorry for their sibling; 3) Being exposed to frightening behaviour; 4) Having empathetic feelings towards their sibling; 5) Hoping the group home will be a relief; 6) Physical violence, affecting relationships.</td>
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<tr>
<td>Bogart, 2015</td>
<td>Nondisabled sibling perspectives on familial relationships</td>
<td>Semi-structured interviews and constant comparative analysis</td>
<td>4, 4 Female, 15-25, Caucasian/American, Intellectual Disability (Downs Syndrome), Both Masters Thesis</td>
<td>1) Nondisabled Siblings as Caretakers; 2) Sibling with a Disability Dependence and the Effect on the Availability of the Caretaker; 3) Impacts of the Sibling with a Disability on the Self.</td>
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<td>Title</td>
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<tr>
<td>Boland, 2021</td>
<td>&quot;Connecting locally: The role of adult siblings in supporting the social inclusion in neighbourhoods of adults with intellectual disability&quot;</td>
<td>Explores the experiences of nondisabled siblings of offering support for local engagement and siblings with intellectual disability of being supported by their brothers/sisters</td>
<td>8, 3 female, 39-61, Irish</td>
<td>1. Intentional and unintentional support for social inclusion, 2. “What I do for them” versus what “we enjoy doing together”, 3. The sibling role as shaped by the family context, 4. Connecting locally with sibling support—the influence of push and pull factors, 5. Service provider involvement—what siblings value and do not value</td>
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<tr>
<td>Chase, 2019</td>
<td>The sibling’s perspective: experiences of having a sibling with a learning disability and behaviour described as challenging</td>
<td>The purpose of this paper is to investigate the effects of having a sibling with a disability and behaviour described as challenging from adult siblings’ perspectives.</td>
<td>6, 6 female, 22-53</td>
<td>1 personal impact, 2 relationships, 3 responsibilities, 4 support</td>
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<tr>
<td>Author</td>
<td>Year</td>
<td>Title</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<td>Davys</td>
<td>2015</td>
<td>Futures planning–Adult sibling perspectives.</td>
<td>15, 12 female, 30-64, British/Asian</td>
<td>University, Peer reviewed</td>
<td>1 future wishes and expectations of care giving, 2 future expectations and wishes 3 concerns for the future.</td>
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<tr>
<td>DePasquale</td>
<td>2014</td>
<td>A sibling's point of view: a participatory action research study of supports needed by siblings of individuals with Intellectual and Developmental Disabilities</td>
<td>7, 5 female, 23-67 caucasian</td>
<td>Doctoral Thesis</td>
<td>1 guilt, 2 obligation, 3 loneliness, 4 embarrassment</td>
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<tr>
<td>Hames</td>
<td>2008</td>
<td>Siblings' understanding of learning disability: A longitudinal study.</td>
<td>12, 7 female, From 2-7 up to the age of 14, UK English</td>
<td>University, Peer reviewed</td>
<td>1 Preschool, 2 Nursery, 3 7-11 years, 4 11-14 years</td>
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<td>Jacobs</td>
<td>2017</td>
<td>It's different, but it's the same': Perspectives of young adults with siblings with intellectual disabilities in residential care.</td>
<td>6, 4 female, 16-22</td>
<td>University, Peer reviewed</td>
<td>1 family relationships, 2 sibling relationships, 3 current life self, 4 current life sibling.</td>
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<td>Kramer</td>
<td>2013</td>
<td>Reciprocity and social capital in sibling</td>
<td>8, 7 female, 32-59, American</td>
<td>University, Peer reviewed</td>
<td>1. sibling relationships build reciprocity</td>
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<td>Study</td>
<td>Methodology</td>
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<td>Moyson, 2012</td>
<td>The overall quality of my life as a sibling is all right, but</td>
<td>investigate how young siblings of children with intellectual disability</td>
<td>University, Peer reviewed</td>
<td>1. Joint activities, 2. Mutual understanding, 3. Private time, 4.</td>
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<td>Leane, 2020</td>
<td>&quot;I don't care anymore if she wants to cry through the whole conversation, because it needs to be addressed&quot;: Adult siblings' experiences of the dynamics of future care planning for brothers and sisters with a developmental disability</td>
<td>Explore how siblings experience future planning.</td>
<td>University, Peer reviewed</td>
<td>1. Developing future plans, 2. Deferring care conversations, 3. Negotiating care roles</td>
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<td>Intellectual disability, Down Syndrome, ASD, Rare Syndromes</td>
<td>Thematic Analysis</td>
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<td>25, 20 female, 22-45, Irish</td>
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<td></td>
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<td>50, 27 female, Dutch speaking Belgian</td>
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21 relationships of people with disabilities. Parents no longer can provide care through enacting family roles, 2. family capital is created through reciprocity of support and through shared experiences and, 3. reciprocity is built through coparticipation in activities and leisure experiences.
<table>
<thead>
<tr>
<th>Study</th>
<th>Title</th>
<th>Sample</th>
<th>Research Method</th>
<th>Analysis</th>
<th>Key Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pavlopoulo, 2019</td>
<td>‘I don't live with autism; I live with my sister’. Sisters’ accounts on growing up with their preverbal autistic siblings</td>
<td>9, 9 female, 12-14, UK</td>
<td>Semi-Structured Interview</td>
<td>IPA</td>
<td>1. Sister's interactions with their siblings, 2. siblings interactions with their parents, 3. Practical struggles of caring, 4.</td>
</tr>
<tr>
<td><strong>Wigley, 2017</strong></td>
<td>Families of people with an intellectual disability: exploring the positives</td>
<td>explore the lived experiences of personal growth for adult siblings of people with ID</td>
<td>Intellectual Disability</td>
<td>Adult</td>
<td>Doctoral Thesis</td>
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<tr>
<td><strong>Yacoub, 2018</strong></td>
<td>Impact of challenging behaviour on siblings of people with autism.</td>
<td>Explore the experiences adults who have a sibling with ASD and intellectual disability (ID) with challenging behaviour</td>
<td>ASD and Intellectual Disability</td>
<td>Adult</td>
<td>University, Peer reviewed</td>
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<tr>
<td><strong>Ying, 2006</strong></td>
<td>Sibling advocates of people with intellectual disabilities</td>
<td>examine the experience of the first generation of sibling advocates in Hong Kong</td>
<td>Intellectual Disability</td>
<td>Adult</td>
<td>University, Peer reviewed</td>
</tr>
</tbody>
</table>

*Atkin 2014 and Atkin 2015 may draw from the same sample*
We conducted a quality appraisal on each of the 20 papers using an adapted form of the critical appraisal skills programme (CASP, 1998; Campbell et al. 2003). This tool was selected due to its usability, adaptability and applicability (Long et al., 2020) Two screener questions are used being, ‘Does this paper report on findings from qualitative research and did that work involve both qualitative methods of data collection and analysis?’ and ‘Is this research relevant to the synthesis topic?’ If either screener question was answered negatively, a paper was not included. A grading system was then implemented using the 10 questions from the CASP. If an item was carried out in the literature, a score of 1 was applied, if this was unsure a score of .5 was applied, and a score of 0 was applied if the CASP item was not carried out. This gave papers quality scores out of 10. This was carried out between two independent assessors and the agreeability between assessors was calculated at 98%.

Although quality varied, no paper was excluded.

Synthesis Method

We proposed to use the Thematic Synthesis (TS) Method described by Thomas and Harden (2008). This involved reading and re-reading the chosen papers note themes and constructs elicited from the primary data. We extracted the findings sections from each paper and inserted this into NVivo software for data analysis. We then coded each line of text according to its meaning and context. We did not include quotes from participants, instead coding researchers’ analyses in order to stay close to the published text and reduce bias. This facilitates the translation of concepts from paper to paper. As new papers are reviewed, codes can be changed, or new codes added. This created a “Codebook” of all relevant codes with associated quotes. Salient quotes were chosen in order to develop a description of each code. Reviewers then looked for similarities between the codes in order to group these into descriptive themes. Once descriptive themes were elicited, these were further explored to develop analytical themes which helped to answer the reviewer’s question as to how
experiences of having a sibling with an LD develop across the lifespan. 30 codes were
organised into 11 descriptive themes and these were subsequently grouped into 5 analytical
themes, and these are detailed in table 2.

**Table 2.**

*Themes and associated codes*

<table>
<thead>
<tr>
<th>Code Names</th>
<th>Descriptive Theme</th>
<th>Analytical Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A sense of loss</td>
<td></td>
<td>Daily Life</td>
</tr>
<tr>
<td>Hassles and stresses</td>
<td>A kind of normal</td>
<td></td>
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<tr>
<td>Feeling Different or alone</td>
<td></td>
<td></td>
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<tr>
<td>Supporting and managing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>disabled siblings</td>
<td>Day to day roles</td>
<td></td>
</tr>
<tr>
<td>Advocating, Fighting, Protecting</td>
<td></td>
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<tr>
<td>Gendered Caregiving</td>
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<tr>
<td>Being neglected or ignored</td>
<td></td>
<td>Coping</td>
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<tr>
<td>The need for support</td>
<td>Seeking Support</td>
<td></td>
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<tr>
<td>The need for training</td>
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<tr>
<td>Using Strategies</td>
<td></td>
<td>Resources and</td>
</tr>
<tr>
<td>Respite</td>
<td></td>
<td>strategies</td>
</tr>
<tr>
<td>Developing sibling relationships</td>
<td></td>
<td></td>
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<tr>
<td>Developing Empathy and</td>
<td>The developing sibling</td>
<td>A Lifelong Commitment?</td>
</tr>
<tr>
<td>Understanding</td>
<td>relationship</td>
<td></td>
</tr>
<tr>
<td>Power dynamics</td>
<td></td>
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<tr>
<td>Sibling Closeness</td>
<td></td>
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<tr>
<td>Shared Tasks and Experiences</td>
<td>The enduring sibling</td>
<td></td>
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<tr>
<td>Rejecting and distancing</td>
<td>relationship?</td>
<td></td>
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<tr>
<td>Future Planning</td>
<td></td>
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<tr>
<td>Future Worries</td>
<td>The Future</td>
<td></td>
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<tr>
<td>The nuclear family system</td>
<td></td>
<td>Shifting Systems</td>
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<tr>
<td>Other Family Relationships</td>
<td>Family and Friend</td>
<td></td>
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<tr>
<td>Other relationships</td>
<td>Systems</td>
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<td>Engaging with services</td>
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<td>Developing service provision</td>
<td>Disability Services</td>
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<tr>
<td>Negative or Difficult Feelings</td>
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<td>Positives and Negatives</td>
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<tr>
<td>Shame, Embarrassment, Guilt,</td>
<td>Negatives Feelings and</td>
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<td>experiences</td>
<td>experiences</td>
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Reflexivity and Validity

In order to increase reflexivity and validity, codes from 6 papers (30%) were reviewed by a second rater. There was general agreement with the codes of the first rater and relevant topics for the discussion were highlighted.

Findings

Analysis resulted in the formation of 5 main analytical themes and 11 descriptive subthemes.

Theme 1: Daily life

This theme related to daily experiences. Siblings expressed positives and negatives but described their lives as “normal”.

A kind of normal

Children sometimes noted the loss of a “normal life” and highlighted a sense of burden which continued into adulthood, when participants highlighted their responsibilities, though children also had hassles and stresses. Childhood stressors consisted of disruption to activities, leisure and schedules, as well as difficulties relating to understanding and stigma amongst friends and the community.

“(Children experienced) shortened sleep and frequent awakenings, issues with homework and study time at home and as well as limited access to leisure activities often as a result of being day and night carers for their siblings” (Pavlopoulou, 2019, p.8)

Child siblings notice differences between themselves and their peers from a young age. Often, they had nobody to talk to about their home life. Children noticed these differences from the
age of 3 on entering nursery. Differences may become more salient in high school years when peer comparison is more important (Hames, 2008). Siblings commented that responsibility made them different and more mature than peers but their lives were “normal for them”. There seemed to be a reconciliatory shift in childhood that allowed children accept their lives.

**Day-to-day roles**

Siblings were engaged in a range of routine, supervisory and advocative tasks. Children began copying care behaviours from their parents from the age of 2 (Hames, 2008) and adopt a care role from a young age. Often there is a tension between parents and siblings about caregiving and siblings are relied on more when parents are unavailable or depleted. In adulthood, siblings adopt a variety of continual caring roles including confidante, trouble-shooter, social secretary, care manager, chauffeur, housekeeper, cook, financial advisor, advocate, personal assistant and ultimately, parent. Additionally in later life, older adults have to consider their sibling’s care as well as their parents’ care.

“... anticipated support roles included financial management and general responsibilities, for example dropping off groceries, providing transport to and from appointments and acting as an advocate.” (Davys, 2015, p.222)

“Another aspect of the sibling’s role in introducing the changes of aging to the family relates to shifting caregiving focus from the sibling with ID to the parents’ needs (Avieli, 2019, p.642)”

Sibling advocacy took many forms. Young children were defensive towards others who might have viewed their siblings as different; this developed into a sense of justice in adolescence which continued into adulthood. Older siblings who were main carers were more concerned with services and resources to manage daily life.
“Many of the participants recognized that they had been advocates for their siblings from the time they were young children and have continued to advocate for their siblings throughout their lives.” (DePasquale, 2014, p.74)

Gender played an important influence with girls specifically being conditioned to “care” for their siblings from a young age. This is reflected by most care work being carried out by mothers and sisters. This is reflected in our current sample of 249, with at least 149 participants (60%) being female, and with many identifying themselves in the primary caring role for their SWD.

**Theme 2: Coping**

This theme describes the coping skills and resources used to manage the responsibility of caring for a disabled person.

**Seeking support**

Unfortunately, siblings highlighted a major lack in support and resources. Both children and adults felt neglected by services and parents. Children longed for additional support and attention; adults were more focused on having a say in their siblings’ care.

“Siblings felt professionals rarely included them in discussions about their brother or sister, offered advice or considered their needs.” (Atkin, 2015, p. 347)

“Adam reflects on his parent’s choice of leaving him out of the family’s “inner circle”. This choice is retrospectively viewed as both compassionate and ultimately wrong.” (Avieli, 2019, p.644)

Children seemingly received more formal and informal support. Some children expressed having friends with SWLD and attending special sibling events. Those that did not highlighted a need for information about disability and sibling support from childhood.
“Two children either deliberately or through mixing with other families with disabled members, had best friends who also had disabled brothers and sisters.”

(Hames, 2008, p.497)

“Where support for siblings is provided, it is likely to be focused on young siblings. Participants expressed a need for ongoing support” (Chase, 2019, p.143)

Child and adult participants highlighted the need for training and education from services, to help them support their siblings. Children from developing regions especially blamed society and governments for service provision. Young children realised they would need help to care for their sibling and hoped to rely on parents in the first instance, as they identified gaps in formal services. Poor services meant siblings had to rely on other family members instead.

“Several siblings connected the failings of early interventions to their current lack of confidence when dealing with their brother or sister’s difficult and upsetting behaviour; and in developing meaningful communication.” (Atkin 2014, p. 234)

Overall, siblings highlighted the need for more comprehensive services for siblings of all ages. While some families felt unburdened having made the decision to use residential care, this was coupled with guilt.

“Thus, all of the participants considered that individual service units should provide training and assistance to facilitate parents and siblings to function independently as advocates.” (Ying, 2006, p.177)

“Participants felt it was important to have interventions that would support and address the needs of typically developing siblings, such as programs for elementary school-aged siblings, siblings in early and late adolescence, as well as adult siblings.” (DePasquale, 2014, p.86)”

The chosen studies suggest siblings can have negative outcomes when support lacking. Childhood experiences with SWLD seemed to take a heavy toll. Half of adults in one study
(Atkin, 2014) had sought formal counselling for mental health difficulties including depression, low self-esteem or anger, related to the past. Others described lacking confidence, anxiety, burnout, breakdown, and health problems, related to a failing in formal services.

“Many siblings mentioned how previous difficulties with service delivery had resonance for their current expectations and anxieties” (Atkin, 2015, p.347)

“Some siblings reported that the family did not receive sufficient help, which increases their anxieties about what to expect from services in the future” (Yacoub, 2021, p.150)

It seemed poor service provision can lead to difficulties with self-esteem and self-efficacy for child siblings. While in adulthood a lack of sufficient training can leave siblings struggling to care for their SWLD, and siblings emphasised that better support would relieve their stress.

Resources and strategies

Strategies for managing behaviour were not frequently discussed. Strategies were more likely to be physical in childhood and included restraint, slapping, hair-pulling and total physical withdrawal: “Sometimes the only way a sibling could feel safe was to lock the door, to stay in solitude in his or her room” (Benderix, 2007, p.414)

Strategies became more nuanced in later life, perhaps reflecting changing attitudes towards the disabled over time, and involved a behavioural management approach.

“Siblings develop different coping strategies to handle this behaviour, such as ignoring the behaviour, trying to understand it or adapting to it.” (Moyson, 2012, p.95)

“The task of identifying triggers was discussed in detail as this led to family members having to adopt a detective type approach in dealing with incidents” (Yacoub, 2018 p.150). So while young siblings sometimes had to use physical means of managing difficult behaviours, older child or adult siblings also used behavioural strategies including
ascertaining triggers, ignoring undesirable behaviour, adapting to SWLD’s behaviour, and trying to understand the function of the behaviour.

Young children expressed the need for respite, to get relief from their usual roles. Older siblings recognized respite as important for going on holiday and managing systemic stress and sometimes sought respite independently of parents.

“Respite services frequently serve as starting points for the emergence of future care plans.” (Leane, 2020, p.955)

**Theme 3: A Life-long Commitment?**

One of the most prevalent themes, sibling relationships are often lifelong.

The developing sibling relationship

Relationships are often lifelong, strong and reciprocal (though many participants were primary carers). Younger TD siblings were often sibling, friend and carer from a very young age. Adult siblings often take on the caring role from mothers, before they pass on the role themselves in old age. Sometimes the next generation of family members become carers, but usually services such as care homes or institutions take over. “Our findings confirmed that sibling relationships were lifelong and reciprocal, often characterised by strong, if ambivalent feelings and loyalties” (Atkin, 2014, p.230)

Sibling relationships develop through reciprocity and shared activities, such as play in childhood and practical activities such as shopping in adulthood, and these are often based on the SWLD’s preference. The needs of the disabled sibling often take precedence and siblings interact often through actions of caring. “To ensure a sense of ease for both siblings, participants tended to downplay their own feelings and followed their siblings lead instead.” (Noonan, 2018, p.1148)

Those with siblings in care often had difficult feelings but knew they would not be able to manage caring for their SWLD and their other responsibilities.
“Ambivalence related to their emotional and practical involvement. Participants all stressed a wish for more contact while also mentioning that this seemed to be difficult or unrealistic…” (Jacobs, 2017, p.16)

Understanding of disability develops comprehensively in childhood. 3-year-olds recognised they are different from their siblings. By 6 or 7, they had a fair understanding of disability and its impact on their SWLD and themselves. By 11 to 14, children had a robust understanding of disability and even genetics (Hames, 2008). They also developed a “social conscience” and got involved in social and political debates on disability and the impact of society on themselves and the SWLD. Empathy for SWLD developed from childhood to adulthood. Difficult feelings were managed through maturity and the example of parents.

“Despite their initial negative assumptions about people with disabilities, (Child) siblings reported moving past the stigma.” (Paul, 2022, p.678)

“They (adult siblings) may have had the opportunity to develop more mature thought processes and develop compassion and patience towards their sibling(s). The ability to show compassion and patience towards their sibling as adults may be due in part to the example that their parents showed them throughout their lives.” (DePasquale, 2014, p.73)

Siblings recognize the power differential between them and their SWLD, from as early as 17 months (Hames, 2008). In adulthood, TD siblings had their own power struggles with parents, services and siblings: “Power tensions pervaded participants’ accounts of their relationships with parents, siblings and the service system.” (Noonan, 2018, p. 1148)

The enduring sibling relationship?

From as young as 21 months, siblings developed closeness. While siblings focused on friend relationships in adolescence, and new familial, social and work relationships in early adulthood, many participants maintained a lifelong sibling bond. Many adult participants
expressed a closeness and feelings of love, caring, attachment and friendliness for their SWLD. This intense bond may propagate responsibility and willingness to care. The SWLD often appreciated this close bond. (Kramer, 2013).

As mentioned, strong bonds develop from a young age through play and leisure time in childhood. Adult TD siblings often instigated outings and shared experiences such as shopping, family rituals and leisure activities or shared in the SWLD’s usual routine. Where children engaged in play more, adult siblings were more involved in practical tasks and family holidays, as well as leisure. SWLD also had relationships with the TD sibling’s children. It is clear therefore that shared tasks and activities are varied throughout the lifetime. However, some sibling relationships (child and adult) did include rejection. Children seemed to reject SWLD from school age, potentially because of embarrassment with peers (Hames, 2008), but also sometimes felt rejected by the SWLD due to communication problems. “On starting school, two parents described how siblings became a little irritated with their brother or sister. (Hames, 2008, p.497)”. This seemed to be short-lived and dissipated with growing maturity. Adults sometimes felt excluded, or excluded themselves, from sibling care. This usually involved a non-primary carer sibling, who was not interviewed, which may leave a gap in the literature. Adult rejection could potentially be more permanent.

The Future

Future plans are “chronically” present but rarely explicit and are often unspoken agreements between parents and siblings, while services are usually oriented on the present. Children might begin thinking about the future from about 11 through to adolescence, and are aware of the future from a young age. Children and young adults are often side-lined however before adopting a carer role at a later stage. Often care falls to one sibling and siblings often decided to take on the care role themselves independently of parents. Siblings often do not expect a further generation to take on a care role: “... she conveyed that when the decision to
become a sibling's caretaker comes from oneself rather than the parents, it can be an **empowering experience**” (Paul, 2022, p.681)

“The Future” was associated mostly with trepidation and anxiety. Adult siblings were especially anxious to discuss the future and their sibling role with parents and services. Parents act as gatekeepers and are sometimes reticent to discuss the future. This adds to the secrecy experienced especially by older siblings around sibling care, and raises their anxiety about the future. “**Siblings felt a particular need to initiate sensitive discussions within the family – and especially with their parents – about the future.**” (Atkin, 2014, p.235)

Families often disagree about where a SWLD should go once parents are gone. Other worries included: challenging behaviour, safety, concerns for changes in their own life, parental death, and finances. Again, worries are less concrete in childhood but began from the age of 4. In summary, children did worry about future care, but this became more of an issue in later life.

**Theme 4: Shifting Systems**

Family systems were dynamic and often changed with age.

**Family and friend systems**

Many participants noted the SWLD often becomes the centre of the family system. In childhood, TD siblings often see themselves on the periphery, until they are required to be carers in adulthood. Mothers are usually the primary carer unless the sibling is required due to her temporary absence, resulting in “role confusion” for children.

“**Three participants described their mothers as being the primary caretaker within the household.**” (Bogart, 2015, p.9)

“**Rebecca uses sports metaphors like “time out” and “sitting on the bench” to unfold the complex experience of always being alert and ready to take over.”** (Avieli, 2019, p.644)

Young adulthood can be a time for siblings to pursue other family and vocational interests before becoming the primary carer later. “**Siblings were especially aware of how their lives**
were sensitive to changing life circumstances. Those beginning their careers, establishing relationships with a new partner, caring for young children had a different set of expectations and choices available to them than say those siblings, whose own children had now left the family home. (Atkin 2014, p.233)” There was a strong sense the family and wider systems were focused on supporting the SWLD throughout their lives.

Siblings often widened and expanded this system when they took over the care role, due to managing many responsibilities. The system can often expand dramatically from parents or just mothers to multiple siblings, their families, the community and services, although the “nuclear family” remains key well into the SWLD’s life. “**However, even the nondisabled siblings who played a central role relied on spouses, children, and/or service agencies.** (Kramer, 2013, p.489)”

Younger adults balanced their sibling relationship with others, but this took more effort as parents relinquished their own duties. Siblings confided in and depended on family members, especially other TD siblings. “**One explained how much having a nondisabled sibling positively impacted the ways in which she has been able to cope with her experiences**” (Bogart, 2015, p.11) However, rejection sometimes caused rifts between TD siblings.

“**Participants also reported that some family members responded differently to the responsibilities.**” (Chase, 2019, p.142) Spouses were often carers also. SWLD often had a good relationship with their TD siblings’ children, but TD siblings were often certain that this generation would not be involved in care. Some peripheral family relationships were problematic, especially in countries where disability is stigmatised. “**One sibling commented on the stigma she perceived from her mother-in-law, who felt that disability was contagious**” (Paul, 2022, p.679)

Children often relied on friend relationships for relief and support, though other children often did not understand the TD siblings’ lives. “**…friends are just important because they**
can help you forget sometimes you're a sibling.” (Moyson, 2012, p.96) Children sometimes found it easier to befriend and rely on other children with SWLD instead (Hames, 2008). Adult siblings struggled to balance sibling relationships with work and social commitments. “Typically, for example, sibling’s contact with their disabled brother or sister was mediated by their busy and unpredictable lifestyles; and their family, social and work commitments.” (Atkin, 2014, p.232)

Adults’ commitment to their siblings often left them isolated, and some had remained single due to caring for their sibling (Boland, 2021). Additionally, adults are sometimes responsible for expanding their SWLD’s social and supportive network also, while their own system is impoverished. “One participant described feeling isolated from her friends due to her family situation” (Bogart, 2015, p.12).

Disability Services

Adult siblings interacted with services through their advocacy, while children attended targeted sibling support groups or workshops. Siblings were regularly unsure about how to engage services, and felt excluded from their SWLD’s care team; rather they were seen as a resource for a crisis by services. Some were happy for services to take the lead, while others were reliant on services and fell into the routine set out by services. “Many siblings commented on how they lacked confidence when engaging with care professionals, a situation sometimes made worse, as several felt unfairly judged by social care staff.” (Atkin, 2014, p.234).

Child siblings understood the role of services well, but wished for services for themselves, especially to teach them to care and advocate for the SWLD. From a young age, siblings understood that services are quite under-resourced or under-developed, especially in developing countries. They related this to social and governmental issues. Siblings seemed more grateful and positive towards services in countries where these services were newly
implemented. “Siblings in both Africa and Asia-Pacific associated the lack of support from their countries’ governments as the root of this issue.” (Paul, 2022, p.681)

**Theme 5: Positives and Negatives**

There were positive and negative aspects to having a SWLD.

**Negative Feelings and Experiences**

Negative feelings expressed by participants included shame, embarrassment, guilt, stigma, fear and resentment which developed from childhood. Young children felt embarrassment and stigma from as young as 3 years. By 7-11, they are cautious about telling others about their sibling. This may even increase in adolescence when peer acceptance is most important. They also develop a social conscience about disability and become more aware of stigma here (Hames, 2008). Older adults felt more shame and guilt, around growing up when their siblings could not. “The type of guilt experienced by siblings is usually in relation to something they feel they ought to do or feel about their brother or sister…” (DePasquale, 2014, p.69)

CB had a profoundly negative effect on siblings and their feelings about the SWD. Children felt loyalty to the SWLD, but this was contrasted with feelings of fear and resentment due to their SWLD’s behaviour and parents’ differential treatment of siblings. Many difficult feelings may begin with social comparison in school. Adult siblings sometimes had ambivalent feelings including responsibility, resentment and guilt. Both adults and children expressed negative feelings about SWLD’s challenging behaviour and this reflected work by Gillespie-Smith et al., (2021) who noted how challenging behaviour impacted negatively on carers’ mental health. Different coping styles may moderate the impact of CB on carers, which may require further study.

Participants also highlighted overtly traumatic experiences involving their SWD. Participants described chaotic childhood family environments, mental and physical trauma, and neglect.
Adults were more likely to face mental harm due to having to care for their sibling, alongside difficult memories of the past. In one study, half of adults had expressed a mental health difficulty which related to their past (Atkin, 2014). “However, despite the best efforts of their parents, nearly all siblings described growing up with a ‘chaotic’ family life” (Atkin, 2015, p.345)

Positive Personal Development

Siblings often identified themselves as being inextricably linked to the SWLD and thought they had no identity separate from their SWLD. They had mixed feelings about their identities but could acknowledge positive personal developments due to their sibling role.

“All participants found themselves to be more mature, responsible, and patient than their same aged peers without a (disabled sibling)” (Bogart, 2015, pp.20-21). Positive traits endorsed by participants included gratitude, maturity, responsibility, patience, empathy, compassion, resilience, pride and being inspired: “On a positive note, some siblings found their experiences as carers from an early age inspiring” (Yacoub, 2018, p.149)

Child siblings developed a lifelong responsibility and devotion from an early age while caring for their SWLD. Responsibility and precocious maturity developed from the ages of 7-11 (Hames, 2008). Responsibilities grew with age and ranged from physical care to holding the system together. Siblings expressed “Pride and Resignation” about this (Boland, 2021). Freedom of choice about care duties were mixed, though there was a heavy bias towards obligation by parents. Despite this some siblings decided to take on the role of carer themselves, which afforded them a sense of pride. “A sense of duty and responsibility, reconciled within the constraints of choice, continued to the present day. Most siblings described and demonstrated a close, affectionate relationship; even those who recalled resentment and anger when growing-up.” (Atkin, 2014, p.232)
Discussion

TD Siblings experienced negative life experiences that their peers did not from a young age (Pavlopolou, 2019; Hames, 2008; Davys, 2015; Avieli, 2019; DePasquale, 2014). This was previously noted by Dyson (2010) who found that TD siblings were more likely to endure negative life events and inconsistent parenting. TD Siblings were involved in sibling care from a young age, but there was a conflict with parents at times as to who was the main carer. Siblings took on a more explicit role when parents were unavailable and in later life (Paul, 2022; Atkin, 2014; Avieli, 2019). This reflects studies which show that children conceptualise disability from a young age and get involved in the care of the SWD from early childhood in order to help parents (Hames, 2008; Stalker & Connors, 2004). Also, other studies have highlighted the changes that occur later in life when adult siblings take over care (Innes et al., 2012). Despite their unique experiences, TD siblings often appeared to want to convey normality in their lives, or a sense that their sibling relationships were no different to other people’s, also seen in Stalker and Connors (2004) research.

Additional stressors required extra support from parents and services (Atkin, 2015; Avieli, 2019; Hames, 2008; Chase, 2019; Atkin 2014; Ying, 2006). However, this was often unavailable to TD siblings who felt neglected. This was previously discussed by Vo et al. (2018) and Coldwell, Pike and Dunn (2008), who noted differential treatment and neglect can lead to difficulties in secure attachment to parents. Children expressed feeling more neglected, while adults more so highlighted being left out of SWLD’s care systems. This was also previously discussed by Innes et al. (2012).

Siblings did not speak broadly about coping mechanisms, and these were very mixed (Atkin, 2015; Avieli, 2019; Hames, 2008; Chase, 2019; Atkin 2014; Ying, 2006). They ranged from often harsh physical reactions to their siblings’ challenging behaviour, to more adaptive behavioural solutions. That families had to resort to physical restraint to manage CB was a
particularly saddening finding. Some children noted relying on physical means of avoiding harm. Sometimes it appeared that children were being restrained inappropriately due to a lack of adequate training or additional support services. Westcott and Jones (1999) have previously discussed how disabled children are more vulnerable to abuse, and the dependent nature of their relationships with family may be a contributing and maintaining factor of this distressing finding. Adult siblings were more likely to engage in adaptive and behavioural methods for managing their SWLD’s behaviour. The changes to the way people managed CB may be reflective of wider societal changes including community access and acceptance of people with LD (Scior & Werner, 2015).

Sibling relationships are often lifelong (Atkin, 2014; Jacobs, 2017; Hames, 2008; Paul, 2022; DePasquale, 2014; Kramer, 2013). TD siblings care for their SWD from a young age, helping parents. They can take a step back in early adulthood and pursue their own lives including social, professional and familial development, before becoming primary carers in later life. This leaves siblings juggling many duties and conflicting relationships, from early adulthood. Professional relationships and work also have to be managed alongside caring duties. Davys and colleagues (2011) have previously noted that sibling roles are frequently subject to changes in age and life stage.

While sibling rejection was not often discussed by participants, this may be because studies often focused on primary carers and future studies may address the opinions of other siblings. Child TD siblings sometimes temporarily rejected SWLD, due to social comparison, embarrassment and stigma and sometimes wanted to hide their SWD from their friends but this dissipated with age.

TD siblings were aware of potential future care roles and were often concerned about the future (Paul, 2022; Atkin, 2014), but this topic was often avoided amongst families. This
caused concerns to grow with age, which was previously demonstrated by Davys et al. (2011) especially when future plans were not openly discussed.

While both children and adults noted being involved with SWLD’s care, adults were more likely to be involved with services. They often felt ignored or neglected by these services and that they were only called upon as a resource during a crisis. (Paul, 2022; Atkin, 2014). This is perpetuated by the chronic under-resourcing of services. Kaur et al., (2009) show that Learning Disability services in the United Kingdom are limited, under-resourced and under-funded limiting a “systemic approach”; while these services are also more sparsely distributed than other services. Power (2009) showed services are limited in the availability, flexibility and choice, due to poor funding, resourcing, and clinician rigidity.

Siblings expressed positive and negative emotions. Children expressed stigma from others and jealousy due to differential parental treatment (Hames, 2008; DePasquale, 2014; Atkin, 2014; Atkin, 2015). This made them feel guilty and ashamed because it was ultimately not the disabled child’s fault. CB caused a range of negative feelings for both all siblings. Participants highlighted traumatic experiences and chaotic family environments during childhood, which has already been noted in Dyson’s (2010) research.

TD Siblings often felt their own identity was linked to their SWLD although they felt some pride for their role; others noted resignation. Positives were focused on aspects of personal development. Several studies highlight mixed outcomes for siblings of CWD (Lobato, 1983; Davys, 2011; Findler & Vardi 2009; Dubnow 2017; Tozer & Atkin, 2015; Stainton & Besser, 2009). Reflecting the present study, many positive outcomes are focused on the development of personal attributes and growth. Differences in outcomes and sibling wellbeing may be due to the wide variety of Learning Disabilities and related conditions including autism, as well as the severity of disability.

**Limitations and future directions**
There were some limitations to the current study. There remains a paucity of research on TD siblings, especially child siblings. Child studies were sparse, representing 7 of 20 studies (35%). Only 3 studies involved children exclusively (Hayes, 2008; Moyson, 2012, Pavlopolou, 2019). Future studies may benefit from a child sibling focus. Studies often focused on primary sibling carers, excluding those with more peripheral roles and over 149 of 249 participants in the current study were female. Other studies also highlight the emphasis on female caring (Block et al., 2019), which may be because women are encouraged to enter domestic and caring fields more than men. This indicates cultural and systematic prejudices around the role of men in caring positions. McDonnell et al., (2019) show that care work is carried out more by women, even in formal services. Given that gender can impact on the ways that people engage in caring activities (Wilson, et al., 2011), it is important that we also get men’s perspectives. Future researchers may therefore wish to further elucidate men’s roles in caring for SWLD. 12 of 20 papers (60%) involved ASD or other disabilities meaning the impact of learning disability alone and the variance in different LDs remains unclear. For example siblings of people with Downs’ Syndrome report more contact, more positive affect, more optimism and better parental relationships when compared with siblings of autistic people (Orsmond and Seltzer, 2007). Future studies may focus on LD without other disabilities. Most importantly, siblings remain neglected in the literature highlighting the need for future research in this group, given how this demographic can already feel on the periphery.

Implications for future research, health and social policy, and practice

From a policy perspective, siblings are often lifelong carers of people with learning disabilities. Professionals may benefit from incorporating siblings into service users’ “care teams” from an early age, not simply relying on these family members as a resource during times of crisis. In clinical practice, child siblings may benefit more from psychological
support targeting those at risk of trauma, as well as interventions which widen the support system by introducing siblings to other sibling carers. Children may also benefit from more information and training on how to care for their siblings from a young age, going beyond current interventions.

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Appendices

Appendix A

Appendix A: Submission Guidelines for Journal of Autism and Developmental Disabilities

Retrieved from: https://www.springer.com/journal/10803/submission-guidelines#Instructions%20for%20Authors_Abstract

Title page
The title page should include:

• The name(s) of the author(s)
• A concise and informative title
• The affiliation(s) and address(es) of the author(s)
• The e-mail address, telephone and fax numbers of the corresponding author

Abstract
Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords
Please provide 4 to 6 keywords which can be used for indexing purposes.

Headings
Please use no more than three levels of displayed headings.

Abbreviations
Abbreviations should be defined at first mention and used consistently thereafter.

Body
• The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
  • Introduction (The introduction has no label.)
  • Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
  • Results (Center the heading.)
  • Discussion (Center the heading.)

Citation
Cite references in the text by name and year in parentheses. Some examples:

• Negotiation research spans many disciplines (Thompson, 1990).
• This result was later contradicted by Becker and Seligman (1996).
• This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author’s name). However, if authors shorten the author group by using et al., this will be retained.

Reference list
The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be italicized.
If available, please always include DOIs as full DOI links in your reference list (e.g. “https://doi.org/abc”).

**Tables**
- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

**Figure Numbering**
- All figures are to be numbered using Arabic numerals.
- Figures should always be cited in text in consecutive numerical order.
- Figure parts should be denoted by lowercase letters (a, b, c, etc.).
- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures, "A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

**Figure Captions**
- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
- Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

**Footnotes**
Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes.

**Acknowledgments**
Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

**Ethical Responsibilities of Authors**
This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct. Authors should refrain from misrepresenting research results which could damage the trust in the journal, the professionalism of scientific authorship, and ultimately the entire scientific endeavour. Maintaining integrity of the research and its presentation is helped by following the rules of good scientific practice, which include*:

Ethics approval
When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

Informed consent
All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images. Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person. Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.
Chapter 2: Empirical Study

What makes you think you’re autistic?- Women’s Perspectives on the Diagnosis of Autism Spectrum Disorder

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Written according to the submission guidelines for the Journal of Autism and Developmental Disorders (See Appendix A)

Word Count (Excluding references and appendices): 9313
Abstract

Autism is a lifelong neurodevelopmental condition which involves difficulties with communication and repetitive, restricted behaviours and interests. Autistic women and their experiences are underrepresented in current research. The diagnostic process has been shown to be long and arduous for autistic women, who are often misdiagnosed. This current study involved interviewing 12 women (6 autistic women, 6 mothers of autistic daughters) to learn about their experiences of the diagnostic process using an Interpretative Phenomenology methodology. 5 superordinate themes were elicited: Expressing and experiencing ASD, Meeting needs and being heard, Identity formation, The Diagnostic Process and Beyond Diagnosis: The Effects of being Diagnosed with Autism. Implications for future practice and research are discussed.

Key Words: Autism, Women, Diagnosis, Mothers, Experiences

1 There is some debate, especially among psychologists, as to whether person-first (people with autism) or identity-first (autistic people) should be used in the literature. While Dunn et al. (2015) posits person-first language is preferred by the American Psychological Association, they concede that disability activists, scholars and autistic people themselves prefer identity-first language. Therefore we will endeavour to use identity-first language in the following paper.
Introduction

Autism Spectrum Disorder (ASD), is a life-long neurodevelopmental condition, which develops in childhood and is typified by difficulties with social communication and repetitive and restricted behaviour (APA, 2013; WHO, 2019 and autistic people present with varied symptoms on a spectrum of severity (Sicile-Kira, 2004). There is a high comorbidity between ASD and other neurodevelopmental disorders such as learning disability (LD), attention deficit hyperactivity disorder (ADHD) and many others (APA, 2013; WHO, 2019). Age of diagnosis can vary from childhood to adulthood and no single test exists for diagnosing autism (Dudova, et al., 2014; Geier et al., 2013; Sturner et al., 2017). Common diagnostic tools include the Autism Diagnostic Observation Schedule; ADOS-3 (Gotham et al., 2006).

Autism in women

ASD is diagnosed more in boys than girls at a rate of roughly 4 to 1 (Fombonne, 2009) and this may be because historically, research focused on male participants (Thompson, Caruso, & Ellerbeck, 2003), as well as diagnostic tools informed by male autistic presentation (Ratto, et al., 2018). However, recent research suggests more parity with rates as close as 2 to 1 (Rynkiewicz et al., 2019). Green et al., (2019) conducted a review on recent literature on autistic women and found differing phenotypes in female autistic people including, psychiatric co-morbidities, and high levels of “camouflaging” or “masking” (behavioural coping strategies to conceal autism symptoms during social situations) (Allely, 2018) which compound the diagnosis of autism in women. Females are thought to mask their social and behavioural difficulties, even in an assessment context, which may cause stress and complicate diagnosis (Ratto, et al., 2018). Gould (2017) masking may also delay diagnosis due to traits being misattributed or unidentified. Lai et al., (2017) suggests masking requires
effort and is stressful, thus contributing to anxiety and depression which may explain autistic women presenting to emergency services more (Tint, Weiss and Lunsky, 2017).

It is particularly difficult to diagnose females without a Learning Disability compared to more profoundly autistic or disabled women who engage in behavioural “stereotypy”. The male to female ratio may fall to 2 to 1 for individuals with significant learning disability. And rises to 10 to 1 for people with superior intellectual ability (Dworzynski, 2012). Therefore those with high intelligence may be better at masking, complicating diagnosis. This leads in many cases to misdiagnosis with other mental health disorders such as borderline personality disorder (BPD) or bipolar disorder, which may also be distressing (Rynkiewicz et al., 2019).

When asked why girls are often diagnosed so late, renowned autistic scientist and author, Temple Grandin elaborated on the subject of masking and its effects saying “Girls tend to be more flexible in their thinking and just don’t show it (autistic traits) and one of the problems with girls with autism is getting into abusive relationships” (Autism Live, 2020). It is hypothesised here that differences in social and cognitive skills may lead to the masking which may negatively impact autistic women’s relationships and wellbeing.

Autistic women also present with physical health comorbidities, including chronic pain and fatigue (Rynkiewicz, 2019; Rydzewska et al., 2018) which makes appropriate service provision difficult (Asztely et al., 2019). Da Walt and colleagues (2021) found that autistic women were at greater risk for health problems such as nutrition conditions, neurological disease, psychiatric conditions, and sleep disorders. Finally autistic females report more negative health outcomes and lower quality of life than typically developing people (Graham-Holmes et al., 2020). Services may be ill equipped to support autistic females around mental health, employment and housing and insensitive to women’s requirements (Tint and Weiss 2018).

**Autism, Gender and Identity**
Late diagnosed women noted pretending to be “normal” (masking) had been stressful, that their gender caused professionals to miss traits of ASD and how having ASD conflicted with traditional female gender identity (Bargiela et al., 2016). The “Extreme Male Brain Hypothesis” (Baron-Cohen, 2002) suggests that autistic men have a polarised, exaggerated “Male Profile” of behaviour and may be supported here however the authors highlight that these findings may relate to developmental trauma or sexual abuse. Brown et al. (2017) suggest that autistic women’s social communication difficulties may make them vulnerable to such abuse.

Autism diagnoses may cause confusion about gender identity (Kanfiszer et al., 2017) and Cooper et al. (2018) noted that there is higher gender variance amongst autistic females, because they might identify less with their own sex, have higher ‘masculine’ and lower ‘feminine’ traits than TD females and have lower self-esteem regarding gender. Bargiela et al. (2016) also noted autistic women may prefer to socialise with men. There was also higher diversity in sexual orientation amongst autistic people in Cooper’s study.

Family implications

Parents of autistic children are shown to experience more distress than other parents (Hayes & Watson, 2013), although this draws on autistic male research and mothers may be most at risk (Freeman, 1991). This may be due to managing challenging behaviour, family functioning and the marital relationships while having to care for the autistic child (Bonis, 2016). Estes et al. (2013) also endorsed problematic behaviour as a major parental stressor. Research on autistic girls highlights mothers finding it difficult to balance the needs of all family members (Stewart, 2012). Parenting groups are often cited as effective (Whittingham, 2009), but parents often had difficulties implementing strategies in the home. These interventions therefore made less impact on parental stress (Allen et al., 2013). Early diagnosis offers timely access to services and professionals, reducing stress and a good
parent-professional relationship can mitigate risk of stress (Elder et al., 2017). As women are often diagnosed later, these gains may not be observed for their parents. Dubnow (2017) also found that siblings of autistic children expressed a range of positive and negative outcomes, including stress and negative feelings towards their autistic sibling. These outcomes could be dependent on the neurotypical sibling’s own resilience and self-concept or the autistic child’s level of externalising and aggressive behaviours, among other factors. Siblings were particularly affected by unequal treatment between themselves and their autistic siblings and, as in the case of parents, by challenging behaviours.

Experiences of the Diagnostic Process

Diagnosis is associated with positives and negatives. Crane et al. (2016) suggest access to services and resources are a key factor, Howlin and Moss (1997; 2012) suggest that diagnosis can help foster a positive identity. Children who are diagnosed early and were aware of their diagnosis described autism and themselves more positively than other children. They were able to speak more about their social strengths compared to children who did not know they were autistic. Females were vastly under-represented in these studies, leaving a large gap in the literature. Anderson and colleagues (2020) studied mothers of autistic females and found that diagnosis empowered them, made sense of their daughters’ behaviours, offered access to helpful resources and legitimised and validated their experiences.

Negatives included stress and stigma associated with diagnosis and assessment (Gillott & Standen, 2007; Botha & Frost, 2018). Diagnostic protocols may also cause autistic individuals to reveal masked behaviours, causing distress and the stigma associated with the label of autism, may cause some people to hide it. Both studies neglected to take gender into special consideration. Anderson et al. (2020), noted mothers expressing a sense of grief due to diagnosis.
Coversely, autistic people may now view autism as part of their identity rather than a deficit (Elliman, 2007) and feel they belong to an autistic community. Since 2000, the autistic community has developed with advances in technology (Bagatell, 2010). Advocacy groups and online resources have helped increase acceptance of autism (Kapp, 2020) and Harmens et al. (2022) found acceptance was a key issue for women going through autism diagnosis. Diagnosis may help people be accepted in the autism community, though this may be more difficult for women.

The current study

Previous studies have lacked the female perspective on the process and consequences of autism diagnosis. Therefore the current study aims to use Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009) to explore the experiences of autistic women and mothers of autistic girls throughout the diagnostic process.

We hope to answer the following research questions:

What are the experiences of autistic women and mothers of autistic girls going through the autism diagnosis process?

What are the experiences of autistic women and mothers of autistic girls following an autism diagnosis?

Method

Participants

Twelve “participants” were interviewed and included in the analysis. 5 were mothers of autistic children aged between 6-15 years old, 5 were autistic females aged 18-35, and 1 was an autistic female, aged 44, who was the mother of a 14 year old autistic child who was interviewed twice (participant 8 and 9). 5 participants were recruited through social media adverts, 2 through the original researcher and 5 through the first researcher’s supervisor. All participants were of white British ethnicity.
Table 1.

Participant demographics

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Population</th>
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<tbody>
<tr>
<td>1</td>
<td>Mother</td>
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<tr>
<td>2</td>
<td>Mother</td>
</tr>
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<td>3</td>
<td>Autistic Female</td>
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<td>Mother</td>
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<td>9*</td>
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<td>11</td>
<td>Autistic Female</td>
</tr>
<tr>
<td>12</td>
<td>Autistic Female</td>
</tr>
</tbody>
</table>

*for the purposes of the study participant 8/9 was treated as two participants, but in fact was the same person talking about her different experiences as an autistic person and mother.

Ethics

Ethical approval was sought from the Ethics Committee at the University of the West of Scotland, to conduct a first study which was carried out by an autistic researcher (referred to as researcher 1 here). Participants received an information sheet and interview schedule prior to interview. They gave written consent to participate and received debriefing documents post interview. Participants could withdraw at any time and refuse to answer questions. Personal data was not recorded and the interviews were therefore anonymous. Records were destroyed post study. Transcripts were securely stored. The second (current) researcher sought ethical
approval from the University of Edinburgh to re-analyse the data. Data was transferred securely via the study supervisor, who owned the data. The research proposal and ethical approval are included in appendices B and C.

Data collection
Due to Covid-19 restrictions, the first researcher communicated with participants via telephone and email, and informed consent was also obtained via email. Participants were interviewed while they were in their own homes and were recorded on Dictaphone over loudspeaker. A semi-structured interview was used to elicit the female experiences of the diagnostic process. Special attention was given to issues of masking throughout. The interview schedule is in appendix D. The 12 interviews were transcribed manually by the first researcher and these were analysed by the current (second) researcher.

Data Analysis
The data were analysed according to the method set out by Smith, Flowers and Larkin (2009). IPA is a bottom-up method whereby the researcher elicits codes from the data, rather than imposing codes which might fit with a certain theory onto the data, as in Grounded Theory. IPA is grounded in the researcher making sense of the way the participant makes sense of their experiences (the double hermeneutic). Therefore, this method is particularly useful for analysing the data available here. IPA is also suitable for studies involving subjects on which little knowledge is available and is also therefore suitable here due to the paucity of other studies examining females experiences of the autism diagnosis process. While IPA may appear similar to thematic analysis (TA), IPA puts greater emphasis on individual experiences by eliciting emergent and superordinate themes in each individual before grouping these together to create a narrative (University of Auckland, 2022).

While Smith et al. emphasise there is no prescribed way of conducting IPA, they offer a broad outline method for use by researchers new to the method, which is adapted here. IPA
focuses on idiosyncratic and individual experiences. Each interview was analysed separately before drawing parallels across interviews. The mother and autistic female groups were joined in this study, due to their shared experiences as females who have experiences the diagnostic process. In addition, children were not included in this study and the mothers included here give voice to these younger children who otherwise would not have been included. Therefore, the analysis was carried out as follows

1) Reading and re-reading transcripts to fully understand participants’ viewpoints before fully analysed each interview in turn, one by one. 2) Initial noting was used to highlight the interesting points from the interviews. 3) From initial notes, emergent themes were elicited by coding the notes. 4) Emergent themes were grouped to form superordinate themes in each interview. 5) This was carried out for all interviews. 6) Once all interviews were analysed group superordinate and subordinate themes were created to capture similarities across individual themes. 7) Quotes were taken from each interview as examples of each theme to form a “codebook” and the most salient were chosen for inclusion in the results. 8) Superordinate themes were grouped into overarching themes and a master theme. A sample of the initial noting and coding is included in appendix E.

Reflexivity and validity

In order for to increase validity and reliability, a third of interviews were co-coded by a second coder (Researcher 3). Reflexivity statements are included for both researchers to highlight the viewpoints and experiences they had which may have affected their analysis of the raw data.

“Researcher 2”

David Berry has taken a specific interest in autistic people in his research at masters and doctoral levels. He also focused on learning disability and autism in his specialist training placements. As part of his role as Trainee clinical psychologist he has conducted autism
assessments with children and adults as part of multidisciplinary teams. He is aware of the complexity of different presentations in diagnosis, including that of females. He was mindful of his experience of patients’ often difficult experiences with obtaining a diagnosis throughout the analysis process. He is physically disabled himself and is aware of some of the challenges faced by disabled/neurodiverse people, although he is mindful of the differences between physical disability and neurodiversity. He has a number of autistic friends and acquaintances.

“Researcher 3”

Lauren Gillies-Walker has supported Autistic people both in a community care setting as a support worker and within education (college level) as an inclusive learning assistant. Lauren was also a staff trainer in the management of ‘challenging behaviours’, working with social care teams to implement support strategies for Autistic people. Lauren is also a family member of an Autistic person who received a diagnosis in adulthood. She therefore has had insight into the diagnostic process and how individuals and their families may be impacted. During data analysis, this allowed her to contribute an in depth understanding of participants experiences.

**Findings**

**The Long Journey to Diagnosis**

16 subordinate themes were elicited, which fell under 5 superordinate themes. These were then organised according to time, using overarching themes. All themes fell under the master theme of “The Long Journey to Diagnosis”. The themes are displayed in table 2.

**Table 2.**

_Themes elicited from participants_

<table>
<thead>
<tr>
<th>Master Theme</th>
<th>Overarching Themes</th>
<th>Superordinate Themes</th>
<th>Subordinate Themes</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Pre-diagnosis: Traversing differences</td>
<td>Expressing and Experiencing ASD</td>
<td>Experiencing Differences</td>
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</table>
and difficulties

<table>
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### Pre-Diagnosis: Traversing Differences and Difficulties

#### The Expression and Experience of ASD

The first superordinate theme “Expression and Experience of ASD” involved the subthemes: the experience of differences, expressing typical ASD traits, the Female Experience of ASD, Changing attitudes, and negative views. We will examine these individually.

**Experiencing Differences**

All participants expressed how autistic females were somehow different to their peers, however, they expressed this difference in various ways with emergent themes such as appearing, feeling, noticing, and being different and developing differently, or being unaware of differences, but later acknowledging they were there. Participant 1 felt different or awkward around others:

“Well she was different from other children as she liked to spend a lot of time on her own (pause). She was very awkward and uncomfortable when around other people although (pause) she was more comfortable with her family members.”
Participant 2 noted how her daughter developed differently to her peers:

“We thought ***** may be autistic as she wasn't progressing as we felt she should, especially like her cousins who are ***** age. We started noticing around 10 months or so she seemed to give less eye contact and wasn't as (pause) engaging as she was months earlier”

Participant 3 noted being different to her peers:

“(…it was the way other people interacted with others and then how I interacted with others (pause) it seems to come naturally to them and to me I had to constantly think.”

Participant 4 did not think of autism but noticed something different about her daughter:

“(… we thought she (pause) had ADHD as her behaviour was erratic, she used to get really worked up if anybody did anything like even look at her, I just didn't think she was a bad child and I wanted to have a reason for why she acted like this..”

Participant 12 had always felt different and stressed, but hadn’t thought of autism either:

“Well (pause) eh I never really thought about autism (pause) until my mum mentioned it to me a while ago.”

It seemed that the participants first noticed differences compared to peers or in development and this may prompt further research or reaching out to professionals.

Expressing typical ASD traits

Despite women having difficulty being diagnosed, the participants expressed noticing clear autism symptomatology of social/communication difficulties and restricted and repetitive behaviours and interests. For example, participant 12 noted social difficulties:

“I struggle to order food even over a phone and I don't like going places as I know I'll see someone I know and that terrifies me. I mean it wasn't like the socialising that scared me it was because I felt I didn't know how to socialise.”

Participant 6 spoke socialising not coming naturally to her:
“it just came naturally to everybody else like making friends and stuff but it didn't come natural to me”

Many participants expressed that autistic females want to socialise but this is difficult. They also exemplified restricted and repetitive behaviour, for example participant 5 noted:

“Well as I said previously she had very difficult behaviour and was very awkward she would refuse to eat as well as being very fussy”

Participant 8 noted common categorising and organising behaviours:

“she used to line everything up and categorise it and sort of put things into categories”

Participant 9 said she had “obsessional” interests, which were actually “special interests”.

“just like having like really strong interests and things, things like obsessional interests, where everyone would say I was so focused so determined and that was because it was classed as a special interest”

Therefore there was a pattern of the autistic females expressing typical traits but these being missed, perhaps due to male stereotypes. Another very typical aspect of ASD is difficulties with theory of mind, the ability to take the perspective of another person. Participant 9 described difficulties with perspective taking:

“I had asked my husband to make the sandwiches and he had actually just made sandwiches for the girls’ lunch and he cut them into triangles so I thought I don't need to tell him as he had just cut them into triangles and he made the sandwiches for the party and he had cut them all into squares rectangles and I went absolutely mad and I just lost the plot”

Here we see how the participant mistakenly thinks her husband will know how she wants the sandwiches made. This difficulty is a clearly autistic trait but had been missed previously.

Comorbidities

Participants noted how concomitant disorders were attributed to mental health issues, rather than autism, potentially due to gender. Concomitant difficulties included obsessive
compulsive disorder, memory issues, reading and attentional problems, other “mental health problems”, anxiety, and depression. For example, when researching about ASD participant 9 said:

“I've watched quite a lot of YouTube videos as I struggle with reading [laugh] it seems to make me fall asleep [laugh] I don't know why.”

Participant 11 said of the anxiety and depression she had previously been diagnosed with:

“I've had many mental health diagnoses since my teens, but they always felt like they were the product of something else and (pause) never quite fit.”

Mental health difficulties may be misdiagnosed or develop because of lack of suitable support. Some women did think their difficulties were not because of poor mental health, participant 12 said:

“I've been diagnosed with anxiety and depression for a few years due to the fact I struggle with day to day things, but I've always thought there was more wrong”.

The Female experience of ASD

Some traits were unique to females, for example “masking”, which is the ability to conceal autistic traits by learning more “typical” behaviours from others. For example, Participant 1 describes her daughter acting “shy”:

“she can go and stay quiet when people are speaking to her and this may then make it look like she's just a bit shy”

Participant 3 rehearsed social situations:

“Well whenever I go into a situation or place (pause) … I always have to think (pause] before I go into that (pause] how I am meant to act”

Participant 9 said she had researched “Love Island” just so she would have something to talk to her colleagues about:
“I went and watched (pause) every episode of love island [laugh] just so I could try and join in with them (laugh)”

This was difficult for her as she wasn’t personally interested in the show. Therefore we see here how females may mask traits to facilitate social interaction. However this is stressful for them and conflicts with male stereotypy. Younger or more profoundly autistic individuals may find masking too difficult, as participant 2 said of her daughter:

‘No ***** does not conceal her autistic behaviours she is just 6 and does not have the understanding to do this’

Masking may be important in order to appear more feminine, and some participants noted acting abnormally was more problematic for girls, for example participant 6:

“…women and girls are expected to be a certain way and that they are expected to be quiet and shy and not be too loud and the behaviours are meant to be perfect [pause] whereas with boy and even men (pause) they can carry on…”

Female stereotypes may have been detrimental to diagnosis according to the same participant:

“Well, I don't know how much training or updated training general doctors get but the first doctor definitely didn't realise that females present differently and can mask their behaviour”

The notion that autistic women need to hide traits or risk being “unfeminine” or “weird” led to doubt about diagnosis, feeling othered and even difficulties with gender identity.

Participant 8 doubted her child’s diagnosis because of her social skills and her own training as a psychologist in the 90’s which focused on the condition being a male disorder:

“… there were too many things about autism that I had been taught, so I thought she can't be because she seems to be sociable”

Being different put participants on the periphery and contributed to isolation. For example, participant 9 said
“I think I had always felt different and I had always struggled to fit in.”

Participant 10 noted: “I don't feel like I fit in with like any of the other kids my age I was absolutely horrible at talking” and “you know, just told you can't have (autism) because I don't know you're a girl or you know you don't have these traits but it's different for everyone”. It appeared that autistic females were othered in neurotypical and neurodivergent groups. This may have led to misdiagnosis and a lack of adequate support as with Participant 12: “I struggle with day to day things, but I’ve always thought there was more wrong as (pause) well considering I had traits that didn't fit with anxiety or depression.” Being unsupported may lead to other difficulties as participant 12 went on to say:

“It actually terrifies me as I can be gullible and people can take advantage of this, so I have to be more careful especially around men as I can sometimes give out the wrong impression without realising”

Participant 1 expressed hope that things are beginning to change amongst professionals and the public however:

“Every single year is improving so that more people are getting diagnosed and understanding about (autism in females)”.

Some negative views were expressed amongst the mothers of autistic females regarding the impact of autism on family life. Participant 7’s daughter had difficulties with “meltdowns”:

“… there are times when I get really embarrassed … We just walk away, and we have to do that because you cannot sacrifice everybody else and she knows this now”. Here we see that difficulties with autistic traits may cause problems for families, acrimony and negative feelings which may lead to isolation and stigma even among families.

Moving Towards Diagnosis

The following themes were pertinent to the period around diagnosis including: validation and invalidation, stress and coping, finding community and identity and Gender Identity.
Meeting Needs and Being Heard

Validation and Invalidation

Another subordinate theme which may be particularly important for autistic females is that of validation and invalidation. Validation is communicating an understanding of peoples’ behaviours, thoughts and emotions and their causes, as well as their viewpoint or experiences (Linehan, 1997), the opposite being invalidation. Participants often felt invalidated before or early in the process of diagnosis. Participant 9 felt invalidated when seeking a diagnosis:

“It's the not being believed that's… the hardest part, people just say aww you're not autistic, there's nothing wrong with you…”

Participant 10 also said:

“My mom and stuff she wasn't so sure about it, but I guess she always known me to be that way she just thought I was a little bit odd you know (pause)”

Family and friends could perhaps reinforce the idea that autism is “bad” and avoid talking about or seeking a diagnosis, thus perpetuating stigma. Autism may also be attributed to “oddness” more so in women.

Invalidation was experienced from varied sources by mothers including healthcare professionals, families and school staff as in the case of participant 5.

“Well to be fair getting her diagnosed was very difficult at first. I raised my ----- concerns with her health visitor that felt her unusual habits were just her age and something she would grow out of but she never did. Also when I raised my concerns with her school they said it was just her age and that she would grow out of the habits she had so they weren't concerned about her learning difficulties but again she never grew out of these. And other family members thought there was nothing wrong either but I did. Plus, getting her to agree to go was probably the biggest challenge as she kept taking a meltdown every time I suggested it.”
Participant 8 noted that her other children did not want her daughter to be diagnosed.

“I think people were going don't be silly there's nothing wrong with her and when I told her sisters they were crying there's nothing wrong, and I was like yeah I know…”

Mothers were more likely to be validated if their daughter was more disabled. For example participant 2’s child was assessed as having autism and a significant learning disability.

“We did not come across any barriers we felt we were heard loud and clear about our concerns and they were taken seriously….”

Equally, if there were other autistic family members participants seemed to be more accepting as in the case of participant 11:

“Well I have been lucky with my family already knowing it was a possibility with me, and with the familiarity from my brother growing up and how similar we are it's meant my mum's support has been there.”

Validation was experienced more during and after diagnosis, as with participant 4:

“Well it's made me feel more reassured, that there is a reason and it's not just her being badly behaved. I can explain it better to people now”

Participant 3 found validation online through her research about Asperger’s Syndrome:

“And after researching it online it became (pause) eh pretty very clear to (pause) me I did have eh Asperger's!!”

Validation/Invalidation emerged as a theme in itself, but also was strongly associated with the Effects of Diagnosis which we will discuss later.

Stress and Coping

Participants described many stressors including daily hassles, difficulties with autistic traits and comorbidities, invalidation and frustration with services. For example participant 4’s child struggled daily with school:
“When she gets home or even before she gets home she'll have a meltdown in the car and really bad, comes in screaming throws herself on the ground and she just won't stop crying” and “she gets stressed or she's too warm or if it's too loud”

Participant 6 noted stress in social situations: “I never really had a lot of friends and I find social gatherings very, very stressful.”

Participant 7 noted how her child was distressed by changes in routine, a very common reporting: “if we go on holiday being in a different place and everything can be really really hard for her”

Participant 12 described emotional difficulties: “I (pause) would always have a lot more of an intense feeling a sort of euphoric feeling so sensory in this sense was good but then when I feel a sort of sensory (pause) overload it it's very distressing”

The women described various coping strategies and discussed ways autistic people self-regulate, soothe and cope with stress. These may develop before and after diagnosis, and the diagnosis may also instigate new strategies. Avoidance was a common strategy. For example, participant 6 noted:

“Basically, my coping strategies when facing stress is to avoid avoid avoid (pause) hideaway from problems (pause) to put things off and eating has always been a big part and is something em I've always done it but I never really understood why”

Participant 12 opted more for distraction than avoidance:

“My coping strategies when I'm stressed about something is to distract myself and surround myself with my friends and family to make me feel better. I also like to try and focus on other things and not think about it much.”

These women used these strategies before diagnosis, but a diagnosis can help explain why certain strategies are helpful. In contrast participant 7 discussed her daughter learning
meditation through CAMHS after being diagnosed: “ah kind of meditation kind of thing so just like from an app to help relax and calm and everything”

Participant 11 used organisation and accepting her “stimming” post diagnosis:
“make a lot of lists as seeing things visually helps me get them done and writing them down helps me split tasks into smaller chunks.”

“…while waiting for a diagnosis and understanding autism I've realised I need to stim but I suppressed it through my life. I've let myself do this now … As I have a history of self-harm I've found allowing myself to stim stops me from getting to that level of distress.”

Diagnosis may legitimise certain strategies and allow autistic behaviours they had kept hidden, using these as coping strategies, resulting in positive mental health outcomes.

**Identity Formation**

The next superordinate theme is Identity formation which comprises of two subthemes, Finding Community and Identity, and Gender Identity, which may form before diagnosis.

**Finding Community and Identity**

This theme involves having and engaging with relationships and community with other autistic people, which helped form positive self-image. Participant 9 was unsure about joining in with the autistic community before her diagnosis:

“like the Scottish woman autism network I've just joined they do these month meet ups so we are now on zoom and I'm too scared to join them because I'm like what are other people on there going to be like emm I'm scared in case they are like people I can't relate to”.

It seemed the wide variation in presentations was a barrier to her inclusion. In contrast Participant 10 said that having a diagnosis explained things for her, helped her find a community and made her feel better about herself:
“… I have made a few friends now and I feel a lot more comfortable with myself now and I'm getting better at talking to people and yeah it had helped me quite a lot”

We see how attitudes were different for participants, however diagnosis may help with acceptance of oneself and thus facilitate entrance into the “autistic community”.

Participant 7’s daughter became more political after researching autism following her diagnosis.

“***** got older she's researched a lot about autism and she's almost like you know really kind of political about it and you know fighting for the rights of sorts of people.”

Her diagnosis has allowed her to engage with the community and advocate for others like her.

Participant 11 was even able to secure a job supporting other people with Autism and Learning Disabilities, following her diagnosis:

“Well since then I've managed to secure my job (pause) it's with Disability Sheffield and I work ten hours a week helping adults with autism and learning disabilities,” It seems therefore that a diagnosis may legitimise a person’s place in the autistic community.

Gender Identity

One of the most interesting themes was that of Gender Identity as research suggests there is a correlation between transgender identity and autism. Given the “male autistic stereotype” it was interesting to see our female participants identify more with males.

Participant 4 noted her daughter’s identifying with boys:

“…she went through a phase of wanting to be a boy, (pause] wearing boy's clothes to school, grey trousers shoes even boxer. She even wanted her hair cut something I could never allow… she also like played with boys, she liked running around, rough play so thought boys had much more fun.”

Participant 9 recalled identifying with her brothers and wanting to play with them:
“as a child I had really long hair I must have been about 10 or something I wanted my hair all cut I had two brothers emm and I just thought the stuff they did was much more fun”

Both of these autistic females identified more with boys and Participant 9 was sometimes mistaken for a boy. This highlights how some women do not relate as much to their own gender for various reasons, and may therefore have diverse gender identities.

**Diagnosis and Beyond**

The experience of diagnosis was split into two main subthemes being: Experiencing the Diagnostic Process, and The Effects of Diagnosis. Here we take the process of diagnosis to mean the time just before diagnosis when the participant is thinking about reaching out to services and typically their visit to a GP, then to specialist services for diagnosis.

**The Diagnostic Process**

**A Long Process**

Three participants explicitly described the process of diagnosis being very long. For example, participant 1 said of her daughter’s diagnosis:

“Well it was a long process (pause) it was it was a paediatrician first initially visited and she then referred her to different departments CAMHS and speech -- therapy who then got together to then make a diagnosis”

The process was long for the family and involved convincing several clinicians. Participant 7 also felt the process was long and difficult:

“It sounds like it was really quick but it's actually over kind of a year of waiting for appointments etc and we filled in a lot of forms asking us lots of questions about her and her behaviour and after having two meetings ***** and spending countless forms and the support of the educational psychologists she diagnosed *****”
Participant 9 noted her own diagnosis took a long time due to her being a psychologist and having to be referred out of her area for an assessment.

“So again, fine was a bit more complex because of my job emm well if we need to see a psychologist we need to request our GP to refer us out of area because otherwise I could be going to see one of our [laugh] colleagues”

A Lack of Knowledge

The lack of knowledge of the public and professionals of the autism in women was difficult. All of the participants in this study expressed this theme which was a prevalent barrier to diagnosis. We summarise interesting observations here.

Participant 5 had noticed her daughter’s difficulties and had asked for help from several professionals but they would not endorse further assessments:

“…the biggest barrier is the lack of information that was available to teachers, health visitors and all those who I raised my concerns with in the first place… they didn't know what the symptoms of autism were or didn't understand my concerns raised”

She went on to describe how people’s ignorance may lead to stigma:

“So, everybody thinks it's just like being handicapped and don't really know what it is and they don't think girls have it, and they think boys are just robots that like to hang about by themselves and that's about it.”

Participant 6’s doctor had misattributed her difficulties to social anxiety:

“Well the first thing I did was go to the doctors and the doctors told me that I wasn't autistic (pause) basically he said 'what makes you think you're autistic’.

Participant 8, a psychologist herself, noted that she hadn’t had any training in the female presentation of autism and that this was a barrier to getting her own child assessed and highlighted the needs among professionals to be trained:
“I did my psychology undergraduate in 1997 to 2001 and we didn’t get taught anything about females, I don’t remember anyway I’m pretty sure it was all about males”

Participant 12 also highlighted how ignorance can contribute to stigma:

“People in society thinking that having autism is embarrassing and weird and that makes you not want to share your diagnosis”

Diagnosis as Triggering

Some found receiving a diagnosis triggering. Participant 2, spoke about how this changed how she viewed herself as a mother:

“What changed my whole thought process. I was no longer a normal mum, I was a special needs mum”

Participant 5’s daughter was reluctant to be assessed and had meltdowns when she was triggered by talking about or going for assessment:

“Plus, getting her to agree to go was probably the biggest challenge as she kept taking a meltdown every time I suggested it.”

Again stigma may discourage pursuing diagnosis. Equally, the diagnosis process may be an overwhelming experience. Interestingly the subtheme of diagnosis as triggering was not highlighted by autistic female participants.

A Positive Experience

Despite the many barriers and difficulties, several participants described having positive experiences of diagnosis. Participant 2’s child had a smoother diagnosis and this may have been due to her having a profound severe learning disability also:

“We did not come across any barriers we felt we were heard loud and clear about our concerns and they were taken seriously in a prompt (pause) very helpful professional manner.”
Participant 8 remarked how she was glad that they had sought a diagnosis through the NHS although it was a long process

“I think one of my friends who was diagnosed and had gone privately coz they can get diagnosed quicker but the NHS wouldn't accept the diagnosis because it wasn't done by them. So, it's probably been an easier route (pause) actually it has been pretty straightforward.”

Participant 10’s friends were also autistic which helped her accept her own diagnosis and made the process easier as she knew what to expect and already had a group to which she would have even more cohesion following diagnosis.

**Validation through Diagnosis**

The process of diagnosis also may have validated the women’s concerns as with participant 2:

“we were heard loud and clear about our concerns”

Participant 4 felt validated and that the process was straightforward:

“It was relatively straightforward, I just took her to the doctors and was referred to CAHMS who asked us loads of questions and then she spoke to a psychologist and from there (pause) and she went to meeting where three separate people were there to confirm the diagnosis.”

Participant 1 felt that the school and her family were more understanding of her daughter once she had received a diagnosis

“Well her primary was then made aware of her diagnosis and then it got extra learning support and (pause) other members of the family were then made aware of her diagnosis and friends and family were a lot more understanding”

Diagnosis helped Participant 5 be believed by the school, professionals and family:

“I think her receiving a diagnosis has had a good impact as I'm now believed and she isn't just a bad child anymore she has she is a child with autism”
A diagnosis of autism also helped her understand some of her child’s behaviours

“So the good thing about it was finally knowing what had caused all these difficulties”

**Beyond Diagnosis: The Effects of Being Diagnosed with Autism**

Diagnosis had various effects on the women and girls. The most common “emerging theme”, endorsed by all participants, was that diagnosis was “functional”. Functions varied from validating, identity formation and community building which we have discussed already, to concepts such as: explaining and understanding, facilitating coping skills, and granting access to resources. For some diagnosis effects included the concept of loss again.

**Explaining and Understanding**

This theme is related to validation but focuses more on *understanding and acceptance* of autistic behaviours. Where the validation concept communicates people see the participants’ perspective, this theme involved *retreat* and of *backing off* by the self and others, so participants felt less persecuted. Participant 1 discussed how diagnosis facilitated others’ understanding of her child and lessened stigma:

“rather than being called a weirdo she is now looked on as just being slightly different”

Similarly participant 7 who had perceived being criticised by her daughter’s school said:

“once I got a diagnosis (for her child) they backed right off as obviously they could understand her a little bit better”

Participant 3 noted how this allowed her to understand herself:

“it's just helped made me understand myself (pause) a lot better”

Participant 6 found diagnosis helped her understand why she had so many difficulties with her emotions

“I can now understand why I experience my pain different from others and I can finally stop searching for reasons why I am so sensitive”
Participant 10 said that she could accept herself more now and that diagnosis “was a relief” saying “I just kind of accepted myself a bit more”.

Participant 12 also said how diagnosis lessened blame and stigma. “The good thing about receiving my diagnosis is --- the fact that I know (pause) it's not my fault eh about the way I act”

Therefore diagnosis may help lessen issues of persecution, stigmatisation and blame of autistic females. Thus diagnosis reinforced that the autistic people were no longer at fault for their different behaviours.

The loss of “normal life”

Many participants also noted that diagnosis made them feel “othered”. For example participant 7 spoke about mourning for the life she thought she would have if her daughter did not have autism:

“when she got her diagnosis for me (pause) it was kind of like a loss I felt like I’d lost the child that I thought I should have”

Participant 8 reiterated this, speaking about how she had hopes for her child that she may no longer meet: “I wanted her to (pause) sort of fit in (pause)"

Participant 10 noted diagnosis meant she was now “different”:

“No really anything was majorly bad about it, there was some. I mean I was different from everyone else.”

Participant 6 said that diagnosis meant people treated her differently:

“I feel as though people don’t really want to tell me anything now, and they don’t really ask me to places”

It seems diagnosis has a transformative effect on the individual, their system and the way others interact and view them.

Resources and Strategies
7 participants noted diagnosis gave access to resources and strategies. Participant 2 wanted to impress that a diagnosis “opened doors” to new possibilities: “Accepting the diagnosis of your child having autism can open doors to therapies and the most suitable education setting that may improve symptoms and their quality of life” and participant 5 said: “Plus her school give her extra time for homework and exams, as well as giving her a quiet place where she could go when overwhelmed, and allowed her to have a list of useful things so she wouldn't forget, plus her teachers would go over things more so she would understand them better.” Participant 8 noted that she had also received resources in school for her child, but also spoke about how a diagnosis allowed for access to social welfare: “they told us in that emm (pause) meeting that she would be entitled to DWP no sorry DLA (pause) disability living allowance which I hadn't even thought about”. Participant 11 even noted that part of the team would go through what she was entitled to after diagnosis: “I've got a follow up appointment to go through everything in a few weeks' time to discuss the additional services available which they also sent out in a booklet”.

In contrast however, participant 7 noted her daughter had not received many resources following diagnosis and that this was unfortunately due to her local authority lacking money, thus people’s experiences may depend on where they live: “I think everyone’s, local authorities are in the same boat, be kind of a lack of money”. Participant 3 noted that not much had actually changed in her life. “I think receiving my diagnosis has (pause) had a good impact on me [pause] but hasn't had a massive impact either because it hasn't really changed (pause) much about my life”.

A diagnosis also helped participants change their behaviours to best help them cope with distress. For example, participant 4 learned to “pick her battles” with her daughter: “I've came up with strategies how to deal with it so instead of saying no I say maybe later”
Before her diagnosis, participant 9 was discouraged from “stimming” to manage her emotions, but has embraced this since diagnosis

“since the diagnosis I was actually reading that it would be classed as stimming and actually it is harmful to take it away and its good for autistic people to do it”

**Discussion**

This study aimed to explore autistic women’s and mothers’ of autistic daughters experiences of the autism assessment process. This “journey” often began by noticing “differences” in themselves or their daughters. Differences included social exclusion, differing from siblings, and a sense of there being something wrong. Kanfiszer and colleagues (2017) also found that autistic women can notice differences between themselves and others. They particularly note differences in socialisation and gender expression. These differences may have prompted independent research, or referral to services. It seemed autistic females may feel excluded from neurotypical and neurodivergent groups.

Participants highlighted late or complicated diagnostic processes often while expressing very clear autistic stereotypy. This is a particularly insidious factor of female autism and its diagnosis, as misdiagnosis (or “missed diagnosis”) can lead to patients not receiving support and having autistic traits misattributed to psychiatric disorders (Gould & Ashton-Smith, 2011; Gesi et al., 2021), which may contribute to the autistic females’ distress and poor mental health outcomes (Isaac et al., 2022). In the current study, participants experienced varied comorbidities such as obsessive-compulsive disorder, memory issues, reading and attentional problems, other “mental health problems”, anxiety, and depression. It remains unclear why this occurs.

We also encountered masking behaviour which may delay diagnosis and distresses autistic females as mental effort is required to “fit in”. This was also observed by Anderson et al., (2020), where mothers described their autistic daughters as “chameleons”, who are
particularly adept “blending in” with others, becoming unnoticed. This was attributed by mothers to autistic females strong masking ability, increased social awareness and gendered social expectations which dictate that girls be quiet, obedient and subservient which reflects other authors’ findings (Ratto, et al., 2018; Gould 2017; Lai et al., 2017). More disabled children were diagnosed more easily, which was also noted by Dworzynki (2012). Those with average or superior intelligence were more likely to be misdiagnosed or have delayed diagnosis. Researchers and clinicians going forward should be aware that autistic people display heterogenous presentations, and that current practices may be insufficient for diagnosing females, although the core symptoms of autism should always be kept in mind.

A number of mothers expressed distress related to their children’s autism. This reflected work by Hayes & Watson, (2013) which highlighted the stress experienced by families, especially mothers of autistic children (Freeman, 1991). Estes et al. (2013) and Bonis (2016) also highlighted challenging or problematic behaviours as being particularly stressful.

We found that participants faced processes of validation and invalidation. Participants were invalidated by not being believed. More specialist clinicians were more likely to validate participants’ concerns. They also found communities online which gave them a sense of belonging. Anderson et al., (2020) noted how mothers felt a sense of legitimacy, and Zener (2019) noted autistic women feel validated through the process of diagnosis.

Throughout diagnosis, females displayed aspects of stress and coping. Participants had many daily stressors and few coping strategies to manage them. Some strategies used were potentially maladaptive and included avoidance and distraction. Later, through diagnosis and ultimately acceptance, some participants were able to find more adaptive methods of coping, such as “stimming”, and formal diagnosis may facilitate acceptance of these. Kapp et al., discuss how a diagnosis of autism, especially early diagnosis, may make behaviours which
are sometimes socially unacceptable, including stimming, *more acceptable*, destigmatising the behaviour and relieving stress.

2 participants displayed gender incongruence which corroborates work by Kanfiszer et al., (2017) and Cooper et al. (2018). It seemed not fitting in with other women made them feel different, while they also displayed some masculine behaviour. For example they wanted to socialise “with the boys”, which was also seen by Bargiela et al. (2016). This may make these women feel more “male”, though more research is required in this topic.

Diagnosis was also seen as a long process, this is also seen by other authors (Dworzynski, 2012; Rynkiewicz et al., 2019; Asztely et al., 2019). Leedham et al. (2020) examined women diagnosed late in life. They expressed a lack of knowledge amongst professionals and the public which led to lengthy diagnostic journeys and stigma. Beyond diagnosis, labelling offered access to resources, explaining and understanding, as also noted by Leedham et al. (2020) However, there was also a loss of normal life which has also been seen by Anderson et al., (2020).

Limitations and future directions

Women adopt most childcare and this is a highly gendered role (McDonnell et al., 2019). Mothers’ may be over-represented in the literature and it may be useful to get fathers’ perspectives in future.

While our participants were female and some had psychiatric diagnoses, all participants were white and British. No further data was collected on social economic status, gender identity (although some participants offered some information on this), or sexual orientation or interest. The exclusion of minorities is an ongoing problem in autism research (Cascio, 2021) which predominantly focuses on white males. In future, more detailed demographic information may lend itself to elucidating the intersections of autistic women in minorities.
Also while white British women may have experienced stressors that others do not, women from other cultures may experience further difficulties, and this may be a useful future focus. The autistic women and mothers were not related in this study. It may have been useful to have recruited mother/daughter dyads so that both these related perspectives of similar experiences could be considered.

Implications for clinicians

The current paper poses several implications for professionals. The pre-diagnosis invalidation faced by our participants reveals a lack of knowledge about autism in women amongst professionals. With these professionals acting as gatekeepers for formal diagnosis, therefore women’s diagnoses are often delayed (Zener, 2019). Further training may be required, especially among Primary Care Staff. It is possible that this is resultant from lacking research of autistic women and their perspectives (Moseley et al., 2021).

Even with specialists, women’s autism can often go undiagnosed or misdiagnosed and they may benefit from further professional development. We noted how one participant was a psychologist herself, but had received no formal training or teaching in women’s autism which highlights the need for further training in psychological and psychiatric professions.

Masking remains a difficulty both for the diagnosis and mental health of autistic women. Formal testing may be overly stressful for autistic women, causing them to shut down. Professionals may therefore need to be extra vigilant to their comfort. There is also a possibility that the current autism diagnosis frameworks, which focus on males, may need to be revised for women. Current diagnostic practices may lead to discrepancies because of professionals’ lack of knowledge, or, ironically, lack of flexibility in applying current DSM or ICD criteria to autistic females. Suckle (2021) posits that the same broad concepts that are applied to males can be applied to women during the diagnostic procedure. Clinicians may however need further training to notice these in autistic women.
Two of our participants exhibited gender diversity which is noted to be relatively common amongst autistic women (Cooper et al., 2018). Conversely, autism is also more common amongst transgender individuals (Jacobs et al., 2014). Professionals may be encouraged to screen transgender patients for autism where appropriate, especially those who are involved in the psychiatric care of individuals.

Participants noted a lack of post-diagnosis services for women, thus post-diagnostic care may be a beneficial focus for services. Diagnosis can be a stressful process and may challenge one’s identity, or evoke feelings of loss. It is important for clinicians to consider this when offering a diagnosis of autism.

Conclusions

Diagnosis is often a long and arduous process for women, who face invalidation, ridicule and stigma, leading to misdiagnosis, or delayed or missed diagnosis. Autism traits are frequently misattributed to psychiatric diagnoses and it appears that typical autism behaviours and traits often go unnoticed. This leads to significant distress for autistic women. Professionals require a greater awareness of women’s autism and related intersectionality (gender, IQ, adaptive ability, culture) so that diagnosis is not delayed.
References


https://doi.org/10.1016/j.braindev.2012.10.004.


Stewart, C. (2012). ‘Where can we be what we are?’ The experiences of girls with Asperger syndrome and their mothers. Good Autism Practice (GAP), 13(1), 40–48


University of Auckland (2022). *Answers to frequently asked questions about thematic analysis.* [https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.pdf](https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.pdf)


Appendices

Appendix A: Submission Guidelines for Journal of Autism and Developmental Disabilities

Retrieved from: https://www.springer.com/journal/10803/submission-guidelines#Instructions%20for%20Authors_Abstract

Title page
The title page should include:
- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

Abstract
Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords
Please provide 4 to 6 keywords which can be used for indexing purposes.

Headings
Please use no more than three levels of displayed headings.

Abbreviations
Abbreviations should be defined at first mention and used consistently thereafter.

Body
- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
  - Introduction (The introduction has no label.)
  - Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
  - Results (Center the heading.)
  - Discussion (Center the heading.)

Citation
Cite references in the text by name and year in parentheses. Some examples:
- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author’s name). However, if authors shorten the author group by using et al., this will be retained.

Reference list
The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.
Reference list entries should be alphabetized by the last names of the first author of each work.
Journal names and book titles should be italicized.
If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

Tables
- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Figure Numbering
- All figures are to be numbered using Arabic numerals.
- Figures should always be cited in text in consecutive numerical order.
- Figure parts should be denoted by lowercase letters (a, b, c, etc.).
- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions
- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
- Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Footnotes
Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments
Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Ethical Responsibilities of Authors
This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct. Authors should refrain from misrepresenting research results which could damage the trust in the journal, the professionalism of scientific authorship, and ultimately the entire scientific endeavour. Maintaining integrity of the research and its presentation is helped by following the rules of good scientific practice, which include*:

**Ethics approval**

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

**Informed consent**

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images. Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person. Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.
Appendix B: Research Proposal

Doctorate in Clinical Psychology

Thesis Research Proposal
(For Methodological Review Only)

This form is for methodological review of projects that are not being submitted as assessed work for Research 1. (e.g. where a trainee has already received a pass mark for Research 1, but subsequently changed the intended thesis project)

The form will be reviewed by a member of the academic team and will receive feedback including an evaluation of the viability of the project and any recommended adjustments. Significant concerns about viability will be flagged to the Programme Director and Research Director and a decision made about whether the project can proceed in its current form.

We expect 2-3 pages A4 for sections 1-8

<table>
<thead>
<tr>
<th>Trainee Name</th>
<th>David Berry</th>
</tr>
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<tr>
<td>Provisional Thesis Title</td>
<td>Spectrum Disorder: The Female Perspective and Experience</td>
</tr>
<tr>
<td>Proposed Setting</td>
<td>Due to the Covid-19 pandemic, all interviews were carried out over the phone from the original researcher’s and participants’ homes. Data will be analysed from the current researcher’s home.</td>
</tr>
<tr>
<td>Allocated Thesis Project Supervisors</td>
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</tr>
<tr>
<td>Clinical</td>
<td>Dr. Katrina Johnston</td>
</tr>
<tr>
<td>Academic 1</td>
<td>Dr. Karri Gillespie-Smith</td>
</tr>
<tr>
<td>Academic 2</td>
<td></td>
</tr>
<tr>
<td>Others Involved</td>
<td>Janie McLaughlan, Dr. Carrie Ballantyne (University of West Scotland)</td>
</tr>
<tr>
<td>Anticipated Month / Year of Submission</td>
<td>February 2022</td>
</tr>
</tbody>
</table>
**Date Form Submitted / Version**

V1

**Please Note:** Whilst this is not an ethics review process, where questions have some similarities to questions contained in the NHS IRAS Research Ethics form, the corresponding IRAS question numbers are given in parentheses. This is intended to facilitate completion of NHS ethics where such approval is needed.

**Section 1: Introduction**

**Provide a brief overview of the rationale and scientific justification for the research**

500 words maximum

*Relevant to IRAS A12*

Autism Spectrum Disorder (ASD), is a life-long neurodevelopmental condition, which develops in childhood and is typified by difficulties with social communication and repetitive and restricted behaviour. Autistic people present with varied symptoms on a spectrum of severity ranging from highly functioning people to more severely disabled. There is a high comorbidity between ASD and other neurodevelopmental disorders such as learning disability (LD) (APA, 2013). Age at diagnosis can vary from childhood to adulthood and no single test exists for diagnosing autism. Stereotypically, ASD has been diagnosed more in boys than girls at a rate of 4 to 1 (Fombonne, 2009) and this may be because most current research focuses on male participants (Thompson, Caruso, & Ellerbeck, 2003), as well as diagnostic tools not acknowledging the different presentation of females with ASD (Ratto, et al., 2018). In addition, females are thought to mask their social and behavioural difficulties, even in an assessment context and this could cause them a great deal of stress, while further complicating the diagnostic process (Ratto, et al., 2018). Finally, parents of children with ASD are shown to experience a greater deal of distress than parents of typically developing (TD) children (Hayes & Watson, 2013), although this conclusion has been drawn largely from studies focusing on males with ASD.

Laughlan and Ballantyne (2021) conducted a qualitative study into the lived experiences of females with ASD and mothers of children with ASD. 12 participants (6 autistic women, 6 mothers) were interviewed and a thematic analysis was carried out on the resulting data revealing three major themes: diagnosis, female ASD phenotype, and misconceptions. Participants describe differences in presentation of ASD in females including masking of symptoms and resulting stress. They describe diagnosis variably as a frustrating but sometimes beneficial process. They finally discuss the misconceptions and stigmatization of ASD resulting from the media’s portrayal of the condition.

As it is apparent that the presentations and experiences of females with ASD, as well as the experiences of the diagnostic process may differ greatly from those of males we would like to conduct further study into this data set. Using Interpretative Phenomenological Analysis (IPA) we hope to further describe the lived experiences of women with ASD through their own experiences and those of their mothers. In particular we are especially interested in the lived experience of families going through the diagnostic process with a female with ASD.

**Section 2: Research Questions / Objectives**

**What are the principal and secondary research questions / objectives?**

*IRAS A10*
What are the lived experiences of women as people with ASD themselves or mothers with daughters who have ASD?
What are people’s experiences of going through the diagnostic process for ASD, with or as a female who has ASD?

### Section 3: Methodology

**Give a summary of your design and methodology**

This should be clear enough for reader to know what will happen at each stage of the project. Include principal inclusion and exclusion criteria and how data will be collected or identified.

**IRAS A13**

**Design**

We are interested in the experiences of women with ASD and their families. A qualitative approach will be taken for this research topic. In order to carry out this research we will analyse transcripts of semi-structured interviews with females with ASD and mothers of females with ASD.

**Participants**

12 participants were interviewed. 6 were females with ASD aged 18-35, and 6 were mothers of females with ASD aged 6-15.

**Settings**

Due to the Covid-19 pandemic, all interviews were carried out over the phone from the researcher’s and participants’ homes. Data will be analysed from the current researcher’s home.

**Procedure for recruitment**

Participants were recruited through the original researcher, the original supervisor and ads placed on Twitter and Facebook.

**Procedure for interviews**

As interviews had to take place remotely due to Covid-19 restrictions, signed consent was sought from participants via email. The researcher called the participants on the phone at a pre-arranged date and time and conducted the interviews on the phone over loudspeaker. The researcher recorded interviews on a Dictaphone for later transcription. Interviews were focused to establish the experiences of women and mothers of the diagnostic process. The interviews with autistic women aimed to establish a female’s diagnostic experience, and the questions included:

- What made you think you had autism?
- Tell me about your experiences of getting diagnosed with autism?
- Can you tell me about your coping strategies when facing stress and have these changed since diagnosis?

And the questions used to gain a mother’s perspective of her daughters’ diagnosis included:

- What made you think your daughter had autism?
- How do you think cultural views of women played a part in perceptions of your
daughters’ behaviour?
- What is it like having a daughter with autism?
- What impact has receiving a diagnosis had on you and what was good and bad about it?

### Section 4: Sample Size

**What sample size is needed for the research and how did you determine this?**

For quantitative projects, outline the relevant Power calculations and the rationale for assuming given effect sizes. For qualitative projects, outline your reasoning for assuming that this sample size will be sufficient to address the study’s aims. If data is to be collected outline reasons for your confidence in being able to achieve a sample of at least this size. 

**IRAS A59 and IRAS A60**

12 participants were interviewed. 6 were females with ASD aged 18-35, and 6 were mothers of females with ASD aged 6-15. McCormack and Joseph (2018) suggest that studies using IPA can involve between 1 and 30 participants with many studies involving only 6. Smith et al., (2009) suggests 10-15 interviews are required for a doctoral project. Therefore a sufficient amount of data should be available for the current study.

### Section 5: Analysis

**Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative methods) by which the data will be evaluated to meet the study objectives**

**IRAS A62**

**Analysis in the current study**

We now hope to analyse data from Laughlan and Ballantyne’s (2021) interviews using interpretive phenomenological analysis (IPA). This method is particularly useful to this project as research into the experience of women with ASD has only been carried out in recent years. IPA is particularly useful for exploring the meanings made by participants of their experiences and uses a double hermeneutic, that is, the researcher makes sense of the way the participant makes sense of their world. This method is especially relevant to subjects where there is a paucity of research according to Smith et al. (2009). The previous study used a thematic analysis to explore the themes evident in patients’ accounts. This IPA analysis will go further to more deeply understand the experiences of ASD diagnosis in women.

Analysis will follow the method laid out by Smith et al. Once data is collected, it is first fully transcribed. While normally it is suggested that research schedules are refined following initial interviews, this will not be done in the current study as the data is already recorded. However, Smith et al. suggest that interview schedules should be used as guides only. Themes will be identified throughout interviews and compared with others. Analysis reveals convergent (shared) themes and divergent (singular) themes. Following this, results can be written up. During this process auditing continues to ensure that emergent themes are supported by the raw data (Smith et al., 2009; McCormack and Joseph, 2018).

### Section 6: Project Management / Timetable

**Outline a timetable for completion of key stages of the project**
E.g. ethics submission, start and end of data collection, data analysis
This project is due for submission in May 2022.

Section 7: Management of Risks to Project
Please summarise the main potential risks to your study, perceived likelihood of occurrence of these risks, and how you will respond to identified risks if they should occur (you do not need to repeat information provided in section 4).

Participants were informed they could withdraw from the study, gave their informed consent were able to skip questions they did not want to answer and were debriefed following the interviews. The only risk to the current study would be a breach of data security which will be addressed by storing transcripts on the University of Edinburgh secure servers and accessing this data on a secured, password protected laptop.

Section 8: Are the any potential costs for the project?
Outline any potential financial costs to the project and justify why these are necessary; including how costs will be met. Please separate these into potential costs for the University and potential costs for your NHS Board. You should ask your NHS Board to meet stationery, printing, postage and travel costs.
There are no costs for the current project.

Section 9: Confirmation of Supervisors’ Approval
“I confirm that both my Academic and Clinical Thesis Supervisors have seen and approved this research proposal and have both completed the supervisors’ appraisal forms below.”

Appendix 1
Main Academic Supervisor’s Appraisal of Project Risk

Supervisor’s Name
Karri Gillespie-Smith

Date
24.8.21

Do you consider that the project should proceed in broadly its current form?
Delete as appropriate
Yes

<table>
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<tr>
<th>Outline the reasons for the above response</th>
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<tbody>
<tr>
<td>Highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks</td>
</tr>
<tr>
<td>There are no known risks.</td>
</tr>
</tbody>
</table>

**References**


Laughlan, J., & Ballantyne, C. (2021) *Autism, Stress, Diagnosis: A Females Perspective*


Appendix C: Ethical Approval

This section is to be completed after review only

ISSUES ARISING FROM THE PROPOSAL – to be completed by Ethics Reviewer

Thank you for your application. We have completed the review process and can provide a favourable opinion.
Signature: Ingrid Obsuth (sig)
Position: Ethics & Integrity Lead
Date: 14 Oct 2021

APPLICANT’S SIGNATURE FOLLOWING REVISIONS – to be completed by applicant

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above underneath each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature:
Student signature:
Date:

CONCLUSION TO ETHICAL REVIEW – to be completed by Ethics Lead

From: HISS Research Ethics <ethics.hiss@ed.ac.uk>
Sent: 14 October 2021 17:05
To: BERRY David ; HISS Research Ethics <ethics.hiss@ed.ac.uk>
Subject: Re: CLPS097 DClinPsy Thesis Ethical Application
Dear David,
Thank you for your application. Based on your response on the application, it meets the standards for Level 1 favourable opinion from the Clinical Psychology, University of Edinburgh Ethics Committee. The signed ethical response sheet/application is attached. If you need to make any changes to the study, please return your amendment to this e-mail with the changes clearly noted in the relevant section of the form.
Good luck with your project,
Ingrid
Ingrid Obsuth, PhD
Ethics & Integrity Lead
Clinical & Health Psychology
Appendix D: Interview Schedule
Appendix 1: Semi-structured interview schedules

Interview questions for the mother of an autistic daughter

1. What made you think your daughter had autism?
2. Were there any specific reasons or behaviours that made you think she had autism?
3. Tell me about your experiences of getting your daughter diagnosed and what was good and bad about it?
4. What have been the implications of your daughter’s diagnosis?
5. Did you perceive any barriers in getting their diagnosis? If yes what do you think caused them?
6. How do you think cultural views of women played a part in perceptions of your daughter’s behaviour?
7. How do you think cultural or societal views of women played a part in perceptions of your daughter receiving a diagnosis? If needed further explanation could mention traditional male/female ratio.
8. What is it like having a daughter with ASD?
9. Do you think your daughters’ behaviours or characteristics and how these were manifesting affected her getting a diagnosis? What were these? (if not mentioned in the previous question) Does your daughter camouflage (i.e. conceal) her autism behaviours? Can you tell me about that?
10. What impact has receiving a diagnosis had on you and what was good or bad about it?
11. Can you tell me about your coping strategies when facing stress? Have these changed since diagnosis?
12. Have you used any Interventions? (ie. Occupational therapy, physical therapy, speech therapy, sensory integration therapy, the use of assistive technology, social skills training, and applied behaviour analysis).
13. Concluding question
   Of all the things that we have discussed today what would you say are the most important issues that you would like to express?

Interview Questions for Females with Autism

1. What made you think you had ASD?
2. Were there any specific reasons or behaviours that made you think you had ASD possibly?
3. Tell me about your experiences of getting diagnosed with ASD. What was good and bad about it?
4. What have been the implications of your diagnosis?
5. What is it like being a woman with ASD?
6. Did you perceive any barriers when trying to get this diagnosis?
7. If there were any barriers, what do you think caused these barriers?
8. How do you think cultural views of women played a part in perceptions of your behaviour?
9. How do you think cultural/societal views of women played a part in perceptions of you receiving a diagnosis?
10. Do you think your behaviours or characteristics (and how these were manifesting) affected you getting a diagnosis? What were these? (if not mentioned in the previous
question) Do you camouflage (i.e. conceal) your autism behaviours? Can you tell me about that?

11 What impact has receiving a diagnosis had on you? What was good or bad about it?

12 Can you tell me about your coping strategies when facing stress? Have these changed since diagnosis?

13 Have you used any Interventions? (i.e. Occupational therapy, physical therapy, speech therapy, sensory integration therapy, the use of assistive technology, social skills training, and applied behaviour analysis).

14 Concluding question
Of all the things we’ve discussed today, what would you say are the most important issues you would like to express?
Appendix E: Sample Interview with notes and codes

Interview 1 - Participant 1
Date: 22nd October 2020

(NOTE: A mother talking about her daughter’s diagnosis when they were 6 years old, which took about 3 years.)

Interviewer: Hello can I speak to ****** please?
Participant 1: One minute.
Interviewer: No worries (pause).
Participant 1: Soz had to leave the room there (pause) noisy kids [laugh].
Interviewer: [laugh] I know how that feels [laugh] is it ok if I begin the interview?
Participant 1: Yes (pause) it’s ****** is it?
Interviewer: Yes I’ll begin then (pause) What made you think your daughter had autism?
Participant 1: Emmm because ****** had different characteristics and behaviours - --- Mannerism compared to other children.
Interviewer: Were there any specific reasons or behaviours that made you think she had autism?
Participant 1: Well she was Different from other children as she liked to spend a lot of time on her own (pause) she was very awkward and uncomfortable when around other people although (pause) she was more comfortable with her family members.
Interviewer: Tell me about the experience of getting your daughter diagnosed with autism?
Participant 1: Well it was a long process (pause) it was it was a paediatrician first initially visited and she then referred her to different departments CAMHS and speech -- therapy who then got together to then make a diagnosis (pause) but it took a long period of time
Interviewer: How long did it take?
Participant 1: I think the whole process was emmm took up to 3 years --
Interviewer: Ok so what was good about the experience of the diagnosis?
Participant 1: Well I felt as though getting her diagnosed meant that it would mean that other people would then understand that her behaviours (pause) were that she would ignore, she was just a little different from others
Interviewer: And what was bad about the experience of the diagnosis? Participant 1: I think not that I would say it is bad (pause) there is just frustrating was (pause) the length of time it took to get her diagnosed because it took nearly three years! I felt as though the process could have been

Note Feeling different from peers, felt daughter was very different to others and didn’t like to interact with others.
Emerging Theme: Noticing Differences

Note Daughter preferred to be alone but would tolerate her family.
Emerging Theme: Typical Presentation (subtle social difficulties)

Note Diagnosis took a long time and involved many different people. This may have made the family feel frustrated/invalidated
Emerging Theme: Diagnosis experience: frustrating/invalidating

Note Diagnosis helped to explain and validate daughter’s different behaviours.
Emerging theme: Diagnosis experience: Validating
a lot quicker and it would have meant we got help quicker.[
Interviewer: What have been the implications of your daughter's diagnosis?
Participant 1: Well her primary was then made aware of her diagnosis and then it got extra learning support and (pause) other members of the family were then made aware of her diagnosis and friends and family were a lot more understanding around her compared to when she wasn't diagnosed.
Interviewer: Did you perceive any barriers in getting the diagnosis?
Participant 1: To begin with no (pause) I think the only barriers were that it wasn't one particular person that made the diagnosis it was made up of various other people who'd unless maybe saw ***** once or twice so they were just going on what they had been made aware from the previous paediatrician so that was only one person.
Interviewer: And what did you think caused these barriers? You were saying about the paediatrician what happened with them?
Participant 1: I think it was just the way they diagnosed it all those years ago I know now that the system of their procedure has changed so you can get diagnosed a lot quicker with her back then you had to go through various different members like paediatrician speech therapist CAHMs Department and it is all about getting passed from pillar to post ----
Interviewer: How do you think cultural views of women played a part in the perception of your daughter's behaviour?
Participant 1: At my daughter's views at the time I felt as well as a bit too young to understand what was happening (pause) she wasn't really aware or made aware that it was autistic sort of processing was going through to see if she would get diagnosed so she was not really sure what was going on. Myself (pause) myself at the time I didn't really know she had autism. that she was shown certain tendencies relating to that (pause) but I was leaving it in their hands to come up with
Interviewer: What What do you think cultural or societal views of women played a part in the perceptions of your daughter when receiving the diagnosis?

Note the length of time for diagnosis is a key issue that can be frustrating. This puts a lot of burden on the family.
Emerging Theme: Diagnosis experience: frustrating

Note Diagnosis functioned as a way of helping others to understand and accept daughter's behaviours.
Emerging Theme: Diagnosis effects: facilitating understanding

Note The process of diagnosis seems to be very frustrating and invalidating because there are so many professionals to convince.
Emerging Theme: Diagnosis Experience: Invalidating

Note Diagnosis can be a confusing process for everyone involved. May not be explained well to patients?
Emerging Theme: Diagnosis Experience: confusing
Participant 1: So we said to (pause) any family members and they couldn’t see anything [pause] see anything different about ***** behaviour?
Interviewer: Ok so was there any difficulties experienced when you took your daughter out or anything like that?
Participant 1: Yeah I definitely did notice a difference in her compared to how other children were acting but again, I think because not a lot of people were Clued up on or testing that I didn’t really know that it was (pauses) that just thought my baby was a bit different but I definitely did see it (pause) definitely, when she was around other children.
Interviewer: So what’s it like having a daughter with autism?
Participant 1: I feel it is all because she got diagnosed young, it was difficult for them, It was difficult for me because like I said previously that there’s not a lot of folk back then had a lot of knowledge on the subject but I feel as though, every single year is improving so a lot more people are getting diagnosed and understanding about it, you know, just treat her like a normal daughter without autism but obviously she’s got it
Interviewer: Do you think your daughter’s behaviours or characteristics or how these were manifested affected her getting a diagnosis and what were these?
Participant 1: Well for (pause) take it back to school, I feel as though it was difficult because teachers felt as though she was just a little bit quiet and shy Whereas the professionals like the paediatrician noticed that it wasn’t just that she was quiet and shy it was showing different behaviours, sitting on the floor hiding behind me, she wouldn’t make eye contact with any of them, she wouldn’t speak whenever asking her just normal questions for her age group and [pause] whereas the paediatricians picked up on that and then that is what helped to basically move it on to get her the diagnosis
Interviewer: So you said she had certain behaviours at school, so does she do this often or does she hides herself or certain behaviours (pause) or characteristics can you tell me about this please?
Participant 1: Well what it can do is she can go and stay quiet when people are speaking to her and this may then make it look like she’s just a bit shy whereas it’s not it’s just because she’s going
through the uncomfortableness. Yeah also what it does is she likes to cover her face by putting her jacket over her or put her head between her knees so that nobody can see her, this is a coping mechanism that she uses, looks weird [pause] as it might just come across to others that is just about quiet and maybe she’s animated
Interviewer: What (pause) has having a diagnosis helped? Has it impacted you in anyway good or bad?
Participant 1: Well by getting a diagnosis we can get extra help for her through school like you said they learn, it now means that people are more understanding towards her so therefore they know that rather than being called a weirdo she is now looked on as just being slightly different because she's got autism and I feel all her friends now accept that and so do our family members.
Interviewer: Can you tell me about coping strategies you have used when facing stress? Have these changed since diagnosis?
Participant 1: Well we just really get on with it, so nothing has really changed.
Interviewer: Have you used any interventions like occupational therapy, speech therapy assistant technology or even applied behaviour?
Participant 1: Well, as I said she used speech therapy during the diagnosis stages. Em, hasn't used occupational therapy I can't really think. I'm not sure.
Interviewer: And finally the last question, of all the things that we've discussed today, what would you say are the most important issues you would like to express?
Participant 1: Well the most important issue that I feel is about the diagnosis as it's a lot more simpler to do now (pause) it's not as long winded as back then the only thing I would say is I feel as though school is where they can hide the autism quite well and teachers are that new in the job that they are afraid to maybe agree with or bring up or pick up any differences in children because they just wanted to make themselves look like they are coping well in the job so I'd say there is more recognition of autism needed at schools
Interviewer: Well that's everything (pause) thank you so much for your time today
Participant 1: Thanks

Note Diagnosis has a function which is to allow autistic people access to resources.
Diagnosis Effects: Getting Help

Note Diagnosis facilitates more understanding from others, will now leave daughter alone and accept her behaviours more?
Diagnosis Effects: facilitating understanding/acceptance.

Note Diagnosis process may be improving over time leaving less burden on the families.
Emerging Theme: Things getting better.

Note Children may be able to mask better in school where they aren't being scrutinised as much
Emerging Theme: Masking

Note More recognition and training on female autism required in schools
ET: Invalidation (by school professionals)
Superordinate and subordinate themes:

**Asd experiences and presentation**
- Appearing and feeling different
- Typical presentation: social disinterest, communication difficulties,
- Women's presentation: masking/shy
- Changing Attitudes

**Validation and invalidation**

**Diagnosis**
- Experience of diagnosis: very long, invalidating, needing a lot of people, needing to convince a lot of people, confusing process, lack of knowledge a barrier
- Effects of diagnosis: functional, explaining, validating,