Exploring the Impact of Autism Diagnosis for Adults with a Learning Disability and their Families

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Abstract

Context: The prevalence of autism diagnosis has significantly increased over the last two decades and this is anticipated to continue. Research has been completed regarding the experience of receiving a diagnosis of autism in the mainstream population; however this has not included people with a learning disability despite the common co-occurrence.

Aim: This study aims to explore the impact of receiving an autism diagnosis for people with a learning disability and their family members.

Method: A qualitative design was used consisting of semi-structured interviews. Participants were adults with a learning disability and their family members who were recruited from an NHS Learning Disability Service; a total of 18 interviews were completed. Data was analysed using reflexive thematic analysis.

Results: The findings consisted of five main themes; Journey to Diagnosis, Understanding, Wellbeing, Support System, and Language. The findings suggest autism diagnosis impacts people with a learning disability and their family members individually and in their interactions with each other. This included gaining greater understanding and acceptance of themselves or their relative, and increased tolerance.

Discussion: Results showed similarities to study findings exploring autism diagnosis in people without a learning disability, however highlighted differences for the learning disability population such as the support they receive and the applicability of assessment tools.

Implications: This thesis highlights the need for greater inclusion of people with a learning disability in autism research. Recommendations include post-diagnostic support for those that would benefit, training for clinicians that support this population, and the possible development of learning disability specific autism assessment tools.

Chapter One: Introduction

Chapter Overview

This thesis explores the impact of autism diagnosis for people with a learning disability and their family members. This introductory chapter therefore contextualises autism and outlines the historical understandings and proposed theories of autism. The impact of autism diagnosis according to current literature is reviewed, which evidences a gap in research on autistic people with a co-occurring learning disability despite the high prevalence of this within this population. Different approaches to conceptualising autism are considered, as well as applications to the field of clinical psychology. The chapter begins with a statement regarding the language that is used throughout this thesis.

Statement of Language

The language that is used in research is value-laden and thus influential in shaping the views of participants and readers (Cluley, 2018; Bottema-Beutel et al., 2021). As this thesis centres around disability, it has been written in a way to intentionally avoid the use of ableist language which assumes that disabled people are inferior to people without a disability, as can be common in research (Bottema-Beutel et al., 2021). The researcher ensured that the language used aligns with recommendations from the National Health Service (NHS) England's Learning Disability and Autism Advisory Group (NHS England, n.d.). Firstly, Autism Spectrum Condition (ASC) is referred to as autism, a more accessible and commonly used term, also used by the participants in this study. Secondly, when referring to autistic people, an ongoing debate exists between the use of identity-first language (IFL) in which the identifier comes before the person, 'autistic person', and person-first language (PRL) where person comes prior to the identifier, 'person with autism' (Dwyer

et al., 2022; Buijsman et al., 2022). There is no global consensus regarding whether IRL or PRL is preferred by autistic people as research has found conflicting results (Botha, 2023; Flowers, 2023). However, due to studies finding a majority preference for IFL, this thesis adopts IFL (Smith et al., 2023; Schuck, 2025). In addition, the term allistic is used to reference people that are not autistic. Allistic is considered preferrable to 'normal' as it frames autism as a difference as opposed to a deviation from the norm (Monk et al., 2022). There are also differences in how learning disability is defined dependent on geographical location and the sphere in which is it being discussed (Higgins, 2014). For example, 'intellectual disability' is used in diagnostic manuals and commonly in academic literature (Cluley, 2018). To share language with the NHS services and participants involved in this research, the term learning disability is used. The full words are also used throughout, as using abbreviations can be considered disrespectful (NHS England, n.d.). As the participants in this study had been diagnosed with autism and a learning disability, they are referred to as autistic people with a learning disability, as recommended by NHS England (n.d.).

Autism

The dominant understanding of autism is the medical viewpoint and currently NHS services that support autistic people operate from this lens (Najeeb & Quadt, 2024). The medical model views autism as a type of neurodevelopmental condition which is present from birth, lifelong, and existent worldwide (Tafolla et al., 2025). The World Health Organization (2024) defines neurodevelopmental conditions as behavioural and cognitive disorders involving difficulties in intellectual, language, social, or motor functions. According to the Diagnostic and Statistical Manual 5th edition (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases 11th revision (ICD-11;

World Health Organisation, 2022), autism is characterised by deficits in social interaction and communication, and restricted, repetitive patterns of behaviour. These characteristics must be apparent from a young age and affect important and multiple areas of functioning (American Psychiatric Association, 2013; World Health Organisation, 2022). Autism is known as a spectrum condition as people's experiences of autism can vary greatly (Alpert, 2021). Autism is recognised as a disability and protected under the Equality Act 2010 (2010) in the UK. The Autism Act 2009 (2009) was also passed in the UK in 2009, being the first disability-specific law in England that was introduced to improve public services for autistic people. As a requirement of the Autism Act 2009 (2009), the government developed a national autism strategy in 2010; this was revised in 2014 and 2021, and an updated version is due to be published in July 2026 (UK Parliament, 20325).

Assessment

Current methods of assessment for autism include self and informant reports regarding current and past behaviour and historical development, and observation utilising validated tools administered by trained professionals. The National Institute for Health and Care Excellence (NICE; 2017, 2021) recommend several diagnostic tools with some variation dependent on age, including the Autism Diagnostic Interview – Revised (ADI-R), Autism Diagnostic Observation Schedule (ADOS), and Diagnostic Interview for Social and Communication Disorders (DISCO). Specialist autism assessment NHS services are now commissioned that solely provide assessment and some offer a limited amount of post-diagnostic intervention. Autism assessment services may support the development of clinical specialists, however assessing clinicians have reported concerns that they prevent a holistic approach being adopted for those who use these services due to their narrow focus (Hayes et al., 2022). NICE's (2014) quality standard states that when people are referred to specialist autism assessment services, their assessment should start within three months of the referral

being made. Due to the significantly outweighed demand, according to the latest released statistics, in December 2025 only 3.6% of patients that had been referred for an autism assessment in NHS services, had a first appointment within this timeframe (NHS England, 2026). NICE (2017, 2021) also recommend post-diagnostic interventions depending on the autistic person's needs. This includes psychosocial interventions aiming to 'improve' autistic people's social interaction and/or interventions to modify 'behaviours that challenge'. It could be argued that these recommendations function to serve the allistic population and inherently aim to shape autistic people into being more allistic if implemented improperly. This links to the double empathy problem which is discussed later in this chapter.

Prevalence

The prevalence of autism diagnosis has increased significantly over the last two decades and may continue to do so (Matson & Kozlowski, 2011; Crompton, 2025). For example, Russell et al. (2022) reported a 787% increase in rates of diagnosis in the UK between 1998 and 2018. Various hypotheses have been put forward attempting to explain the reason for the increase, including changes to diagnostic criteria, increased general awareness of autism, and greater emphasis on earlier diagnosis (Matson & Kozlowski, 2011; Russell et al., 2022).

Prevalence rates have been estimated according to age, sex, and geographical location. The World Health Organization (2025) estimated that in 2021, approximately one in 127 people worldwide were autistic. In Zeidan et al.'s (2022) systematic review to determine the global prevalence of autism in children, they found that 1% children had received a diagnosis. Issac et al. (2025)'s study estimated 0.77% children had been diagnosed with autism globally and reported differences dependent on continent with the highest prevalence in Australia, then Africa, America, Europe, and fewest in Asia. This supported Salari et al.'s

(2022) systematic review which found prevalence rates of autism were 1.7% in Australia, 1% in Africa, 1% in America, 0.5% in Europe, and 0.4% in Asia. Maenner et al.'s (2023) surveillance study completed in the United States found in 2020, one in every 36 eight-year-old was autistic. Brugha et al. (2016) studied prevalence rates in adults in England and found 1.1% met criteria, but many had not been formally diagnosed.

It is well-documented that a higher prevalence rate has been found in males compared to females (Napolitano et al., 2022), for example, Zeidan et al. (2022) found double the number of boys had been diagnosed to girls. However, there may be factors influencing researched prevalence rates outside of sex differences. Females tend to be diagnosed at later ages impacting autism statistics and are theorised to mask their symptoms more than males (DaWalt et al., 2021; Cruz et al., 2025). In addition, diagnostic criteria is based on autistic males; autistic females may present differently therefore not meet criteria, highlighting the need for a female autism phenotype to be considered (Cruz et al., 2025). There are also newer theories considering the relationship between autism and gender diversity. Bonazzi et al. (2025) analysed gender diversity in autistic people by completing a meta-analysis consisting of 14 studies and based on their findings concluded that gender diversity is more common in the autistic population compared to allistic people.

As well as sex and gender, characteristics such as race and socio-economic status are found to impact timing of diagnosis. Valicenti-McDermott et al (2012) found that children of Hispanic and African American origin, foreign-born children, and children born to foreign mothers were more likely to be diagnosed later. Similarly, Daniels & Mandell (2014) found that white children were more likely to be diagnosed earlier, and children from racialised groups were more likely to receive misdiagnoses and access specialist services later. In addition, they found that families with a higher socioeconomic status were more likely to access support thus obtained diagnoses sooner. This supports Thomas et al.'s (2012) research

which concluded children from higher-income communities receive autism diagnoses sooner than those from lower-income communities.

Co-occurring Conditions

Research has found higher rates of co-occurring conditions in the autistic population than the allistic population. This is even the case where under-reporting occurs due to the identification of co-occurring conditions being more complex in autistic people due to social communication differences, and the presence of diagnostic overshadowing in which difficulties are wrongly attributed to known conditions (Rydzewska et al., 2018; Casanova et al., 2020).

Physical health comorbidities have been found to occur significantly more frequently in autistic people (Sala et al., 2020). Rydzewska et al. (2021) completed a meta-systematic review and found autistic people were more likely to have neurological conditions such as epilepsy, gastrointestinal and metabolic issues, immune disorders, and sleep disturbances. Ward et al.'s (2023) study supported this when they found higher rates of gastrointestinal, neurological, endocrine, visual, skin, liver and kidney, and haematological conditions in autistic adults and adolescents. Due to the increased risk of physical diseases, Steinhausen et al. (2025) suggest autistic people are offered comprehensive routine medical monitoring during developmental and adult years.

Mental health difficulties are also more common in people with neurodevelopmental conditions including autism (Mammarella et al. 2022). In Lai et al.'s (2019) systematic review examining the prevalence of mental health diagnoses in the autistic population, 70% of autistic people had been diagnosed with a mental health condition. The most common was an anxiety disorder, followed by a depressive disorder, a mood disorder, and least commonly a psychotic disorder (Lai et al., 2019). In alignment with this, Tromans et al. (2018) found a

greater prevalence of autistic people in inpatient psychiatric settings compared to allistic people.

Additional neurodevelopmental conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Developmental Coordination Disorder, and learning disability are also more likely in autistic people (Saito et al., 2020). Saito et al. (2020) researched co-occurring conditions in autistic children and found only 11.5% had autism as their sole neurodevelopmental condition. Rodríguez-Quiroga et al. (2025) similarly found high rates of co-occurring ADHD in autistic children. Hollingdale et al. (2024) suggest an accumulative effect, finding young people with multiple neurodevelopmental conditions experience greater difficulties including cognitive, social, and behavioural problems than those without a co-occurring condition. The high prevalence of co-occurring conditions in the autistic population evidence the need for comprehensive, multidisciplinary care (Rodríguez-Quiroga et al., 2025) which specialist autism assessment services are unable to provide. It is crucial for autistic people to be offered holistic care as co-occurring conditions can significantly affect quality of life, result in poorer health outcomes, and lead to premature mortality (Casanova et al., 2020; Sala et al., 2020).

Learning Disability

One of the most common neurodevelopmental conditions to co-occur with autism is learning disability (Matson & Shoemaker, 2009). The DSM-5 (American Psychiatric Association, 2013) and the ICD-11 (World Health Organisation, 2022) define learning disability (termed intellectual disability) as a disorder characterised by impairments in intellectual and adaptive functioning, present in childhood, and can be classified as mild, moderate, severe, or profound. Both manuals direct users to specify whether someone has an accompanying learning disability within the diagnostic criteria for autism due to the high

prevalence of co-occurrence. Ziedan et al.'s (2022) study reported the median percentage of autistic people with a learning disability was 33% worldwide. Similarly, Rydzewska et al. (2018) found 30% of autistic people in the UK also had a learning disability, and Maenner et al. (2023) estimated between 32-38% of children with autism had a learning disability in the US. Based on estimates that 20-30% of autistic adults have a learning disability, Emerson and Baines (2010) suggest between 35,000-58,000 access social care services in England. Despite the high rates of co-occurring learning disability in the autistic population, there is currently no specific autism assessment tool for people with a learning disability. This is problematic as autistic people with and without a learning disability can present differently and have different needs (Matson & Shoemaker, 2009). Autism in people with a learning disability is more likely to be under or misdiagnosed (Hurley & Levitas, 2007). This can prevent this population from accessing effective support, and research has already highlighted autistic people with a co-occurring learning disability have worse health outcomes (Dunn et al., 2019). Autistic people with a learning disability are also significantly underrepresented in research on autism, which fails to represent a high percentage of the autistic community (Russell et al., 2019). Due to this, less is known regarding the needs of this population, and the possibility of evidence-based practice is therefore restricted (Reuben et al., 2025).

Historical Understandings of Autism

The definition and diagnostic criteria for autism has changed greatly over time (Cook & Willmerdinger, 2015). Throughout history different terminology has been used to describe autism. The term autism was first used in the early 20th century by Bleuler, a Swiss psychiatrist, who viewed this as a symptom of schizophrenia (Greydanus & Toledo-Pereyra, 2012). Following this Sukhareva, a Russian psychiatrist who specialised in children,

separated autism from schizophrenia using the term ‘autistic pathological avoidant psychopathy’ (Lang, 2025). This was significant as Sukhareva was the first to distinguish autism as its own condition (Manouilenko & Bejerot, 2015). This was built on by American psychiatrist Kanner (1943), who described what he called infantile autism; Kanner was known for arguing that autism was caused by parenting and suggested that parents change how they raise their children (Lang, 2025). At a similar time Asperger, an Austrian paediatrician, referred to ‘autistic psychopathy’ during his work with boys with characteristics of autism (Mintz, 2017). This was subsequently known as a subtype of autism and coined Asperger Syndrome by British psychiatrist Wing (1981). In line with historical understandings, autism was deemed part of childhood schizophrenia within diagnostic manuals until the third edition of the DSM where it was included as a separate condition; ‘pervasive developmental disorder’ (Mintz, 2017). Within the following edition, the DSM-IV, pervasive developmental disorder contained five subcategories including ‘autistic disorder’ and ‘Asperger disorder’ (Mintz, 2017). This was then revised, including the removal of Asperger disorder and autism became known as a spectrum condition, currently considered ‘Autism Spectrum Disorder’ in the DSM-5 (American Psychiatric Association, 2013). As part of this revision the clinical features of autism are currently understood within a dyadic model comprised of social communication difficulties and restricted and repetitive behaviours (Grzadzinski et al, 2013).

Theories of Autism

A variety of theories and models have been put forward attempting to explain autism, from cognitive, social, and developmental approaches. Some of the most prominent concepts are outlined below, however many others exist.

Starting with cognitive approaches, one of the early models is the Theory of Mind deficit suggested by Baron-Cohen et al. (1985). Within this Baron-Cohen et al. (1985) conceptualise theory of mind as the ability to comprehend other people's separate mental states including their beliefs and emotions. Following their experiments with autistic children, they hypothesised that autistic people lack this ability and are therefore unable to consider and predict other people's thoughts and actions, affecting their social communication. Baron-Cohen (2002) later built on this suggesting cognitive processes, such as mentalising, vary according to sex and developed the Extreme Male Brain theory of autism. The Extreme Male Brain theory proposes that females engage in 'empathising' which involves identifying with and responding to others' emotions, whereas males engage in 'systemising' which consists of analysing variables in a system to identify the governing rules (Baron-Cohen, 2002). The Extreme Male Brain theory hypotheses that autism equates from having an extreme male cognitive profile (regardless of the sex of the person), consisting of limited ability to empathise and strong ability to systemise, impacting social relationships.

Reporting that the Theory of Mind model fails to explain all characteristics of autism, Frith & Happe (1994) proposed the Weak Central Coherence theory. Central coherence refers to the integration and grouping of information during cognitive processing, in order to view things as a coherent whole. Frith & Happe (1994) suggested that autistic people process fine details but have difficulty conceptualising information holistically, which impacts their ability to mentalise and understand others. Closely positioned to the Weak Central Coherence theory, autistic researcher Dinah Murry devised the Monotropism theory of autism (Murry et al., 2005). The Monotropism theory of autism argues that autistic people experience attentional processes differently from allistic people. It proposes that allistic people pay broad attention to a range of stimuli which they call polytropism, whereas autistic people channel attention narrowly into singular stimuli (Murry et al., 2005). They advise that this explains the

restricted and repetitive behaviour characteristic of autism and differences in social interaction.

Following multiple hypothesised theories conceptualising autism through a cognitive lens, social considerations of autism started to emerge such as Milton's (2012) Double Empathy Problem. Milton, an autistic scholar, highlighted that the above theories are based on assumptions of 'normality' that autistic people must deviate from, positioning them as defective. Locating differences in social communication as autism deficits ignores the relational foundation of social interaction, failing to acknowledge the presence of allistic people and mutuality of relationships. The Double Empathy Problem demonstrates that difficulties in social communication between autistic and allistic people are experienced by both parties and stresses the lack of empathy autistic people receive as autism is framed as a condition consisting of a lack of theory of mind and the ability to empathise with others (Milton, 2012). Milton (2012) builds on this by suggesting autistic people are actually likely to understand allistic people more than be understood by them themselves, as they have to exist in a society built for allistic people. In extension to this, Shaw et al. (2024) suggest the Triple Empathy Problem which highlights another empathy gap autistic people experience from the healthcare system. Shaw et al. (2024) interviewed autistic people regarding their experiences of healthcare and found they had faced multiple barriers extrapolated by the culture within medical settings including healthcare professionals and the systems themselves. This gap will exist in education, social care, and justice systems as well as within healthcare, disadvantaging the autistic population (Shaw et al., 2024).

Impact of Autism Diagnosis

Managing the difficulties associated with neurodevelopmental conditions can have a significant impact on families (Gardiner et al., 2018). As well as the individuals themselves, caregivers often experience strain and siblings can feel overlooked (Corcoran et al., 2015). The journey of seeking diagnosis can itself be arduous and challenging, and the receival of this is experienced differently (Simon et al., 2022).

Research has been completed exploring people's experiences of autism diagnosis, with parents of autistic children and autistic people diagnosed in adulthood. In Ooi et al.'s (2016) meta-synthesis, parents reported experiencing a range of difficult emotions when their child was diagnosed with autism including shock, despair, and anger. In addition to this, Legg and Tickle (2019) found parents felt a sense of guilt, and concluded parents require support themselves post-diagnostically. Studies on autistic people diagnosed in adulthood have yielded more positive results. Kiehl et al. (2024) found before diagnosis people felt different from others, and learning they were autistic gave a sense of relief and clarity. Similarly, Gellini and Marczak (2024) found diagnosis improved people's understanding of themselves and led to greater self-acceptance. For some being diagnosed enabled self-compassion to replace self-criticism (Wilson et al., 2023). However, Corden et al. (2021) found this was dependent on self-esteem, with lower self-esteem linked to dissatisfaction with autistic identity, and higher self-esteem linked to autistic pride.

Evidencing Russell et al. (2019) and Reuben et al.'s (2025) claims that autistic people with a learning disability fail to be included in autism research, there is no research regarding how this population experience the receival of diagnosis. This is despite the fact that a large volume of autistic people also have a learning disability. This highlights a significant gap in the literature.

Despite the positive impact autism diagnosis can have, clinicians should be conscious of the heavy emphasis diagnostic criteria places on ‘deficits’ (Crompton, 2025). Possibly due to this, many autistic people choose not to share their diagnosis with others due to fear of negative judgement (Fletcher-Watson, 2024). Interestingly, in Gardiner et al.’s (2018) study exploring the impact of neurodevelopmental conditions, diagnosis itself carried little impact as this does not equate to emotional and behavioural functioning. This highlights the need to consider how neurodevelopmental conditions are conceptualised.

Conceptualisations of Neurodiversity

The way neurodevelopmental conditions are conceptualised carries considerable impact for people including how they perceive themselves, how they are perceived by others, and how services operate, all of which significantly affect health, wellbeing and quality of life. Several different approaches to this are outlined below.

The Medical Model of Disability

The medical model of disability portrays disabilities as abnormal and endeavours to ‘treat’ disabled people to align with ‘normality’ (Zaks, 2024). This has significant impact on disabled populations as they are seen as ‘other’, causing social exclusion (Babik and Gardner, 2021). From the medical viewpoint, autism is seen as difficulties within an individual that need correcting (Pellicano & Heyworth, 2023). Note the use of the term ‘deficit’ in diagnostic criteria as opposed to ‘difference’. As mentioned earlier, NICE (2021) guidelines propose interventions to ‘modify’ autistic people’s social communication. The medical model has been criticised for its reductionistic and harmful approach, however, remains dominant in society. For example, stating someone has social deficits minimises the complexity of social relationships (Knapp, 2019). In addition, the need for a female autism phenotype highlights

the biased nature of diagnostic manuals, excluding a significant amount of the population (Whiteley et al., 2021).

The Social Model of Disability

In retaliation to the medical model, the social model of disability coined by British sociologist Mike Oliver, emerged from the British disability rights organisation, the Union of the Physically Impaired Against Segregation (Berghs et al., 2019; Oliver, 2023). The social model argues that rather than disability being a difficulty rooted in an individual, difficulties arise from societies failure to include and accommodate disability (Oliver, 2023). This approach drives for the removal of societal barriers disabled people face and calls for attitudinal change (Berghs et al., 2019). This viewpoint alleviated shame and enabled solidarity for disabled people (Shakespeare, 2004). From this approach, autism is not seen as collection of deficits, but a mismatch between the needs of autistic people and mainstream environments. This calls for the eradication of stigma and increased inclusion and accessibility within society (Bertilsdotter et al., 2025). Woods (2017) argues the social model is yet to be implemented for autistic people due to society's mass reluctance to adapt to individual needs, to continue to serve the allistic population.

The Neurodiversity Movement

Building on the social model of disability, came the neurodiversity movement. The term 'neurodiversity' has often been attributed to autistic Australian sociologist Judy Singer; however, its origins may have been more collective stemming from other autistic and neurodivergent communities (Botha et al., 2024). The neurodiversity movement argues differences in neurological functioning is an inherent part of the human condition, as opposed to there being 'normal' and 'abnormal' categories (Dyck & Russell, 2019). This approach recognises the interaction between disability and the environment (Dwyer, 2022) but

normalises difference and stresses the need for societal adaption as opposed to treatment (Lang, 2025). Following the term neurodiversity, an American autism rights activist, Kassiane Asasumasa, coined the term ‘neurodivergent’ (Zaneva et al., 2024). This was used to distinguish people with neurodevelopmental conditions such as autism, ADHD, dyslexia and dyscalculia from the general population which is neurodiverse in terms of natural variation in neurological functioning. American scholar Walker also coined the term ‘neurominority’ to highlight the social marginalisation that neurodivergent people experience (Walker & Raymaker, 2021). This was built on by Benson (2023) who proposed ‘compulsory neuro-normativity’ which refers to the societal pressure neurodivergent people face to fit into existing systems that fail to serve them. The neurodiversity movement considers autism a part of identity that can be celebrated (Kapp et al., 2013). Dwyer et al. (2024) explored autistic people’s views on the neurodiversity movement and found this was highly supported. Stating the neurodiversity movement is gaining greater attention within psychological professions, Flower et al. (2023) developed a list of core principles of neuro-affirmative practice with clinicians that support autistic people and autistic people themselves. This includes minimising deficits and highlighting strengths, recognising and attempting to overcome systemic barriers, and adapting care to suit individual needs.

Applications to Clinical Psychology

There are many implications for the field of clinical psychology in how best to support autistic people. Within clinical practice, clinical psychologists can ensure they are formulation led to meet individual needs as opposed to positioning people by diagnostic category. This supports transdiagnostic ways of working which enables people to be viewed more holistically and has been found to have greater utility than diagnostic led treatments

(Van Os et al., 2023). This also accounts for possible co-occurring conditions autistic people are more likely to experience. Clinical psychologists can support people post-diagnostically and whilst validating the challenges autistic people experience, reframe deficits as difference (Gellini, 2022). Alongside this they can ensure work is driven by and for the autistic person, in accordance with their goals, and that necessary accommodations are implemented. Clinical psychologists can also be conscious of biases in assessment tools and complete more comprehensive assessments. In their indirect work, clinical psychologists can offer training to other professions regarding autism and advocate for autistic populations. As part of this, they can ensure to work collaboratively with autistic people, as well as in service development initiatives and clinical research. Clinical psychologists also have a duty to challenge inequality and discrimination in order to support social change.

Conclusion

This chapter has introduced autism including diagnostic criteria, prevalence rates, co-occurring conditions, and assessment methods. A brief history of autism is then outlined, followed by different ways autism has been theorised. Different approaches to conceptualising neurodevelopmental conditions are introduced, as well as subsequent considerations for the field of clinical psychology. The impact of autism diagnosis was also considered which identified a significant gap in the literature; autistic people with a learning disability have not been included in this, despite the high rates of this co-occurrence. To be better informed to address this gap, the following chapter reviews relevant literature regarding learning disability.

Chapter Two: Systematic Literature Review

Chapter Overview

This chapter presents a review of current literature completed to guide and inform this thesis. Due to the scarcity of available research on autism within the learning disability population, a review focused specifically on this topic was not viable. Instead, this literature review focuses on the question "how do parents experience their child being diagnosed with a learning disability?". This provides a foundation for what people with a learning disability and their family members may have experienced prior to autism diagnosis, impacting their receipt of this. A meta-ethnography was completed to achieve this, and four overarching categories were identified: Grief Processes, Experiences of Services, Relationships with Others, and Attitude towards Disability. A line of argument is proposed explaining the interplay of these. The chapter concludes by considering gaps in knowledge and outlining the subsequent aims of this thesis to address these, as well as how the results of the literature review can inform the current research.

Aim and Rationale of the Literature Review

Attempts to gather and review literature regarding people with a learning disability as part of this project posed challenges due to the scarcity of research including the learning disability population. Limited studies directly involving people with a learning disability were found, including none regarding the receival of a co-occurring diagnosis of autism. Studies that have been conducted exploring autism diagnosis have been completed with parents of autistic children (Legg & Tickle, 2019; Ooi et al., 2016; Corcoran et al., 2015) or autistic adults that do not have a learning disability (Wilson et al., 2023; Gellini & Marczak, 2024; Kiehl, Pease & Hackmann, 2024). Therefore, to contextualise this project by

considering the historical experiences of participants, a literature search regarding the experience of receiving a diagnosis of a learning disability was completed. Demonstrative of the paucity of research involving those with a learning disability, few studies were found that involved individuals receiving this diagnosis themselves (Shewan et al., 2012; Kenyon et al., 2013). Focus therefore shifted on to the experiences of parents of people with a learning disability, who are often heavily involved and thus influential in the lives of people with a learning disability due to the support they provide throughout the lifespan. Knowledge regarding parents' experiences is also valuable as it provides a foundation for what families may have already experienced prior to an autism diagnosis being given, which way influence the way that this is received. The aim of this literature review was therefore to explore the question, "How do parents experience their child being diagnosed with a learning disability?" in relation to the published peer-reviewed literature.

Method

Design

To align with the aim of the literature review, a qualitative synthesis approach was selected. Qualitative research increases understanding of people's experiences of healthcare, thus qualitative syntheses are being increasingly used to guide health related policy and practice (Dixon-Woods et al., 2005; Barnett-Page & Thomas, 2009). A meta-ethnographical approach was adopted. As well as synthesising findings across studies, meta-ethnographies develop higher level concepts to enable new insights (Sattar et al., 2021). Noblit and Hare's (1988) seven step guide to meta-ethnography was followed. This incorporates getting started; deciding what's relevant; reading the studies and assessing quality; determining how studies are related; translating the studies; synthesising translations; and expressing the synthesis.

Article Selection

Search Strategy

To effectively identify relevant and appropriate literature, Cooke et al.'s (2012) search strategy tool for qualitative research, SPIDER, was used. This defines key elements of research to support the identification of search terms. The completed SPIDER tool is displayed in Table 1. Terms across headlines were combined using 'AND' between each category. 'Design' was not included to prevent the limiting of results.

Table 1

Organisation of search terms utilising the SPIDER tool.

SPIDER Headline	Search Term Used
Sample	Parent* OR caregiver* OR mother OR father OR guardian AND
Phenomenon of	Child* OR kid* OR offspring AND
Interest	Diagnos* AND
	"Learning disability* OR LD OR "Intellectual disability* OR ID OR "Developmental disability*" OR "Developmental delay" OR "Learning difficult*" OR "Mental retardation" OR "special needs"
Design	
Evaluation	Experienc* OR perception* OR attitude* OR view* or feeling* OR perspective* OR account* OR express* OR explor*
Research Type	Qualitative OR "grounded theory" OR "thematic analysis" OR narrative OR interview* OR "focus group"

Inclusion and Exclusion Criteria

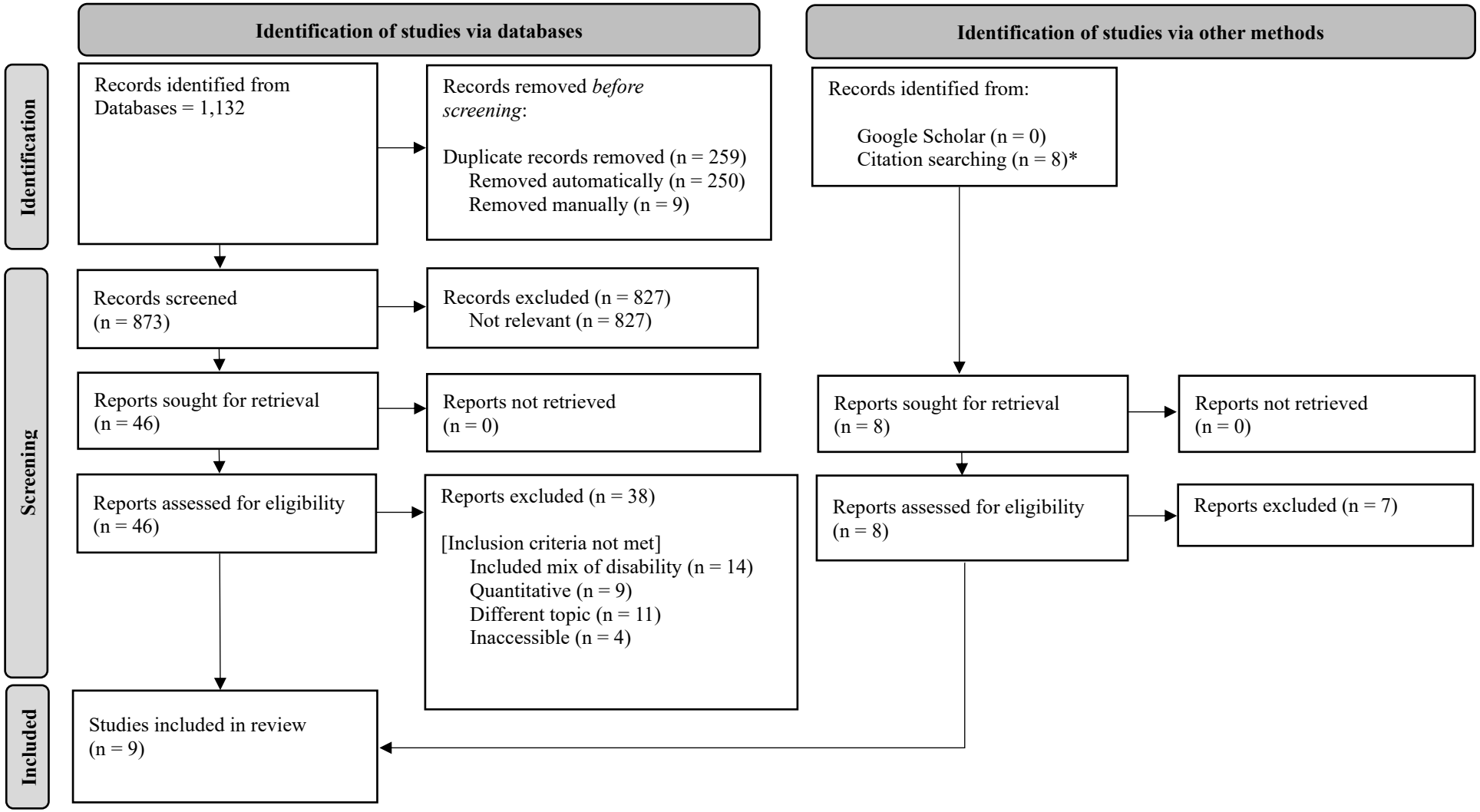
Criteria was established to ensure eligibility of the studies used. Papers had to be written or translated into English. Studies were only included if they contained qualitative data; papers utilising mixed methods were considered if qualitative data was distinguishable, and quantitative data and exclusively quantitative papers were excluded. Participants had to

be parents of a child with a learning disability and if other family members or caregivers were included in the sample, parent's reports had to be decipherable. Studies had to include the receival of a diagnosis of a learning disability instead of a diagnosis of a different neurodevelopmental condition such as autism; many utilised the term learning disability but on exploration a different diagnosis had been given. Studies had to focus on parents' experiences of learning the diagnosis; papers were considered if other processes such as supporting a child with a learning disability were considered as long as experience of diagnosis was also apparent.

An electronic search was conducted using the final search terms on the following databases: APA PsycInfo, APA PsycArticles, APA Psych Tests, MEDLINE Ultimate, and CINAHL Ultimate. A year range was not set to maximise results. The final search yielded 1,132 results. Before screening 259 duplicates were removed: 250 automatically and nine manually. A total of 873 papers were screened and 827 were excluded due to irrelevance. Google Scholar was also searched however produced no new papers. Eight further papers were found through citation searching; therefore, a total of 54 papers were reviewed for eligibility. Due to not meeting inclusion criteria or meeting exclusion criteria, 45 papers were excluded. The remaining nine papers were deemed suitable: Fernández-Ávalos et al. (2020), Davenport (2020), Marsh et al. (2018), Sheehan & Guerin (2017), Brown (2013), Broberg (2011), Bostrom et al. (2009), Partington (2002), and Budak et al. (2018). A PRISMA flow chart (Page et al., 2021) presenting the process of article selection is displayed in Figure 1.

Figure 1

PRISMA flow chart outlining article selection.



Note. *Papers found via citation searching are identified in Table 2.

Results

Studies took place in Spain, the United States, the UK, Ireland, Australia, Sweden, and Turkey. Samples included a mix of mothers and fathers, mothers only and fathers only. Eight of the studies carried out interviews and one completed a focus group. An overview of the key features of each study is presented in Table 2.

Quality Assessment

To examine the credibility of each study, a critical appraisal tool from the Critical Appraisal Skills Programme (CASP, 2023) orientated to qualitative research was used. This was applied to each paper; the results are presented in Table 3.

All papers stated their aims and appeared to use aligning methodology and appropriate recruitment strategies. Within each, analysis was rigorous and findings were presented clearly. Studies considered their own contributions and limitations, however only two papers considered the relationship between researcher and participant; this is particularly important in qualitative research due to its influence on data collection (Watt, 2007). In addition, only 5 explored ethical considerations; others only stated ethical approval had been granted. As is a common limitation in qualitative research, sample sizes were limited across studies (ranging from 6-25). Aside from Marsh et al.'s (2018) study, mothers were generally represented in greater numbers than fathers. In addition, studies were completed in the UK, Ireland, Spain, Sweden, US, Australia, and one in Turkey reflecting a range of nationalities but all were westernised societies. This limits how representative the findings are as non-western cultures were not included. It is also possible, given the nature of the research, that those who have adjusted and are coping well are more likely to participate, therefore the presence of bias must be considered. Following quality assessment all papers were included in the synthesis; however, strengths and limitations were considered.

Table 2

Key features of each study.

Author	Country	Sample	Data Collection	Analysis	Themes
Fernández-Ávalos et al. (2020)	Spain	16 parents (11 mothers, 5 fathers)	Semi-structured interviews	Grounded Theory	Reception of the diagnosis Emotional bonds with the child Experience of loss and feelings in response to intellectual disability diagnosis Recurrent grief Coping strategies
Davenport (2020)	United States	25 parents (24 mothers, 1 father)	Semi-structured interviews	Phenomenological Analysis	Age of becoming a special needs parent Initial emotional reactions Types of support available Stress impact Obstacles to stress reduction Stress strategies utilised Solutions to prevent compassion fatigue Parental suggestions
Marsh et al. (2018)	Ireland	10 fathers	Semi-structured interviews	Narrative Analysis	The visible and invisible nature of an intellectual disability Emotional downturn; Shock and disappointment, Grief and loss, Denial and blame
Sheehan & Guerin (2017)	Ireland	11 parents (8 mothers, 3 fathers)	Semi-structured interviews	Thematic Analysis	The early years Later experiences What helps in the early years Engagement with professionals Provision of information on emotions
Brown (2013)	Australia	6 mothers	Semi-structured interviews	Thematic Analysis	Initial diagnosis; expectation and realisation The solemnity; double mourning The personal; reaction and response The societal; exclusion and inclusion Pivotal point; crisis and coping Milestones; lost and found The future; challenge and change

					Meaning making; identity and agency
Broberg (2011)	Sweden	17 parents (9 fathers, 8 mothers)	Semi-structured interviews	Discourse Analysis	Tragedy and the lived experience Tragedy and the outsider perspective The clinical gaze The super-parent ideal
Bostrom et al. (2009)	Sweden	17 parents (9 fathers, 8 mothers)	Semi-structured interviews	Interpretative Phenomenological Analysis	Emotional expressions regarding the child Experience of the disability Time orientation
Partington (2002)	UK	6 mothers	Focus group	Burnard's (1991) data analysis steps	Antenatal diagnosis Cycle of bereavement Issues relating to causation Examples of poor interpersonal skills
Budak et al. (2018)*	Turkey	17 mothers	Semi-structured interviews	The Hermeneutic Method	Impact Burden of Care Change Stigma Uncertainty Search for Meaning

Note. *Budak et al. (2018) was found in Fernández-Ávalos et al.'s (2020) citation list.

Table 3

Quality assessment of nine papers using the CASP tool.

Author	Was there a clear statement of aims?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Fernández-Ávalos et al. (2020)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Discussed strengths, limitations, future research
Davenport (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Considers significance of the study, limitations, implications, future research
Marsh et al. (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Discussed strengths, limitations, future research

Sheehan & Guerin (2017)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Discusses strengths, limitations
Brown (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Discusses limitations, future research, implications
Broberg (2011)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Includes some strengths, limitations, future research
Bostrom et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Discusses limitations, clinical implications
Partington (2002)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Includes some implications
Budak et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Includes strengths, limitations, credibility, implications, future research

Relations and Translations

The results of each study were analysed to examine how they relate or differ to each other. To achieve this, results were carefully and repeatedly read, and the key themes and concepts within each paper were identified. The presence of each was then checked across papers to identify translations. Twelve key concepts were found: Shock, Denial, Sadness, Guilt, Anxiety, Acceptance, Diagnostic Journey, Interactions with Professionals, Social Support, Feeling Different, Judgement from Others, and Embracement. Table 4 displays the occurrence of each concept across papers.

Table 4

Key concepts across studies.

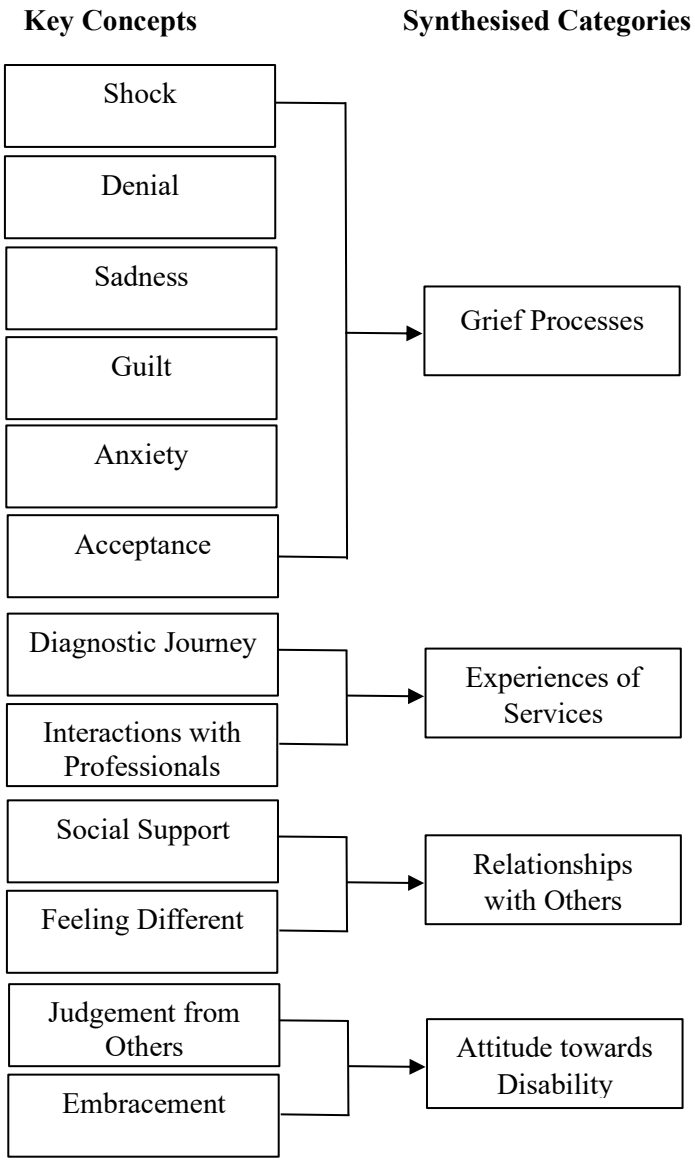
Paper **Concept**	Fernández-Ávalos et al. (2020)	Davenport (2020)	Marsh et al. (2018)	Sheehan & Guerin (2017)	Brown (2013)	Broberg (2011)	Bostrom et al. (2009)	Partington (2002)	Budak et al. (2018)
Shock	X		X		X				
Denial	X		X	X	X			X	X
Sadness	X	X	X	X	X	X	X	X	
Guilt	X	X	X	X		X		X	
Anxiety	X	X		X	X	X	X		X
Acceptance	X			X	X		X		X
Diagnostic Journey	X	X	X	X			X	X	
Interactions with Professionals	X	X	X	X	X	X		X	
Social Support	X	X	X	X	X	X			X
Feeling Different	X			X	X	X			X
Judgement from Others				X	X	X	X		X
Embracement	X	X	X	X	X				X

Synthesising Translations

Key concepts were shared and reciprocal across papers with minor refutations, therefore they were synthesised into broader categories. This was achieved through examining the relationship between concepts, and four categories were established: Grief Processes, Experiences of Services, Relationships with Others, and Attitude towards Disability. Figure 2 illustrates this process.

Figure 2

Key concepts and synthesised categories.



Grief Processes

Parents reported experiencing a variety of different emotional responses to the diagnosis including shock, denial, sadness, guilt, anxiety, and acceptance, which can be understood as grief processes.

Shock

Many parents reported feelings of shock on learning their child has a learning disability. This was an instant reaction to diagnosis (Fernández-Ávalos et al., 2020; Marsh et al., 2018; Brown, 2013), as their expectations were challenged by the presence of the disability (Brown, 2013). Intensity of shock appeared to vary; the shock of parents whose children were diagnosed later were less intense, potentially due to having had suspicions (Fernández-Ávalos et al., 2020).

Denial

Parents also shared experiencing denial which presented in various ways. Some denied anything was different about their child in general (Marsh et al., 2018), whereas others did not believe the diagnosis, or believed it was wrong (Brown, 2013; Fernández-Ávalos et al., 2020; Partington, 2002). Some parents also minimised the impact of the learning disability, and/or believed their child would recover in time (Fernández-Ávalos et al., 2020; Budak et al., 2018).

Sadness

Sadness was also commonly used to describe parents' emotional response to the diagnosis (Fernández-Ávalos et al., 2020; Davenport, 2020; Sheehan & Guerin, 2017; Brown, 2013). Parents associated this with loss; loss of the ideal or expected child, and loss of their anticipated future due to how they anticipated their lives will be affected. Some parents also

reported feeling sad due to perceiving that their child was suffering due to the learning disability (Fernández-Ávalos et al., 2020). The presence and intensity of sadness appeared to vary; some parents reported that it reoccurred long after the diagnosis and was triggered at life milestones (Sheehan & Guerin, 2017; Brown, 2013).

Guilt

Parents also shared experiencing guilt associated with two main themes. Many felt guilty due to thinking the learning disability may have been caused by something they did, or that they could have prevented it somehow (Fernández-Ávalos et al., 2020; Davenport, 2020; Marsh et al., 2018; Partington, 2002). Others also reported feeling guilty for some of the thoughts and feelings that they had about their child on learning they had a learning disability (Marsh et al., 2018; Sheehan & Guerin, 2017). Guilt led some parents to criticise themselves which may have hampered their acceptance of the diagnosis (Fernández-Ávalos et al., 2020).

Anxiety

Parents described feeling worried, stressed, and fearful in relation to their child's learning disability. They worried about their future, associated medical interventions they required, and how other people would treat them (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017; Budak et al., 2018). Parents advised they subsequently felt very overprotective of their child and some reported hoping that that they died together so their children were not left without them (Fernández-Ávalos et al., 2020; Budak et al., 2018). Parents also felt anxious about themselves, whether they would be able to be good enough parents for a child with a learning disability, and whether they would be able to cope (Sheehan & Guerin, 2017).

Acceptance

With time most parents reported reaching acceptance of the learning disability diagnosis, as family life became more settled and comfortable (Fernández-Ávalos et al.,

2020; Sheehan & Guerin, 2017). Having a child with a learning disability became part of ordinary life, and parents highlighted that having children without a learning disability has its own challenges (Bostrom et al., 2009; Sheehan & Guerin (2017). Some parents described experiencing a shift in perspective, where they viewed things more optimistically and realised their own ability to cope (Brown, 2013).

Experience of Services

Parents shared their experiences of services in relation to the diagnosis and the impact that this had, including obtaining the diagnosis and how they received medical professionals.

Diagnostic Journey

Many parents reflected on the process they underwent to gain their child's learning disability diagnosis which was commonly found to be challenging and arduous. Many spoke of the hardship in getting their child tested, as medical staff appeared dismissive of their concerns or suggested they give their child more time to develop which caused parents frustration (Marsh et al., 2018; Bostrom et al., 2009). The testing process itself was also stressful for parents due to having to attend numerous appointments, misdiagnoses along the way, and the attempt of multiple interventions (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017; Bostrom et al., 2009). Some parents also felt excluded from the decision-making process which felt disempowering (Partington, 2002). Gaining the learning disability diagnosis was an important step for parents (Marsh et al., 2018), however many were not satisfied with how this was received (Partington, 2002).

Interactions with Professionals

Parents experiences of healthcare professionals impacted how they received their child's diagnosis and the ongoing support that they accessed. Experiences appeared to be mixed and varied across timepoints. Parents commented on professionals' delivery of the diagnosis, the negative prognosis their child was given, and the assumption that parents would view the learning disability negatively, all of which invoked feelings of anger towards healthcare staff (Partington, 2002; Brown, 2013; Fernández-Ávalos et al., 2020). They also reflected on the need to focus on their child's shortcomings in order to access support from professionals and services, how challenging this process can be, and the lack of acknowledgement they received regarding the impact this has on them (Broberg, 2011; Davenport, 2020). Despite these negative experiences, some parents reported they received invaluable support and described professionals as helpful and understanding (Sheehan & Guerin, 2017). Some built trusting relationships with professionals who lifted their spirits and whom they looked forward to seeing (Sheehan & Guerin, 2017).

Relationships with Others

Parents described how their child's learning disability was received by people in their social network and how this affected their relationships with others including family, friends, and other parents.

Social Support

Similarly to their reports of working with professionals, parents shared mixed experiences of social support. For some, family members provided a lot of support which some described as essential (Davenport, 2020; Fernández-Ávalos et al., 2020). Whereas other parents felt those around them provided very little support and did not understand their

situation (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017). Parents also reflected on how their own relationship was impacted by their child's diagnosis. Some couples experienced tensions: this was linked to feelings of blame towards one another, and/or feeling alone or unsupported (Marsh et al., 2018; Brown, 2013; Budak et al., 2018). Some however felt the experience of the diagnosis brought them closer together (Budak et al., 2018). Many parents highlighted the benefit of mutual support through being with other parents with children with a learning disability; they felt other parents understood them and helped them feel less alone in how they were feeling (Sheehan & Guerin, 2017).

Feeling Different

Another common experience parents reported was that of feeling different from others and like 'an outsider', which affected their social relationships (Fernández-Ávalos et al., 2020). Some expressed feeling different due to their children having different needs, requiring more practical support, and needing to access services (Sheehan & Guerin, 2017; Davenport, 2020). Many reported a tendency to compare themselves to others, comparing their children with other children and themselves with other parents, which exacerbated feelings of difference (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017; Brown, 2013). Some parents felt marginalised within social settings, and some were actively excluded and/or lost friends (Sheehan & Guerin, 2017; Brown, 2013; Budak et al., 2018).

Attitude towards Disability

Parents reflected on the impact of differing attitudes towards their child's learning disability, including other peoples and their own.

Judgement from Others

Other people's attitudes regarding their child's learning disability significantly impacted parents' experiences. Parents reported feeling supported when others responded positively, congratulated them and expressed joy regarding their children (Sheehan & Guerin, 2017). However, many experienced negative judgements from others which evoked feelings of sadness and shame (Sheehan & Guerin, 2017; Brown, 2013). Other people's pity due to their perception of their child was particularly unwanted (Sheehan & Guerin, 2017; Broberg, 2011). Some parents reflected on how wider society views people with a learning disability and shared they and their children had been exposed to social discrimination (Bostrom et al., 2009; Budak et al., 2018). Due to the impact of other people's judgements, many parents either hid or were very mindful of who they talked to about their child's learning disability diagnosis (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017).

Embracement

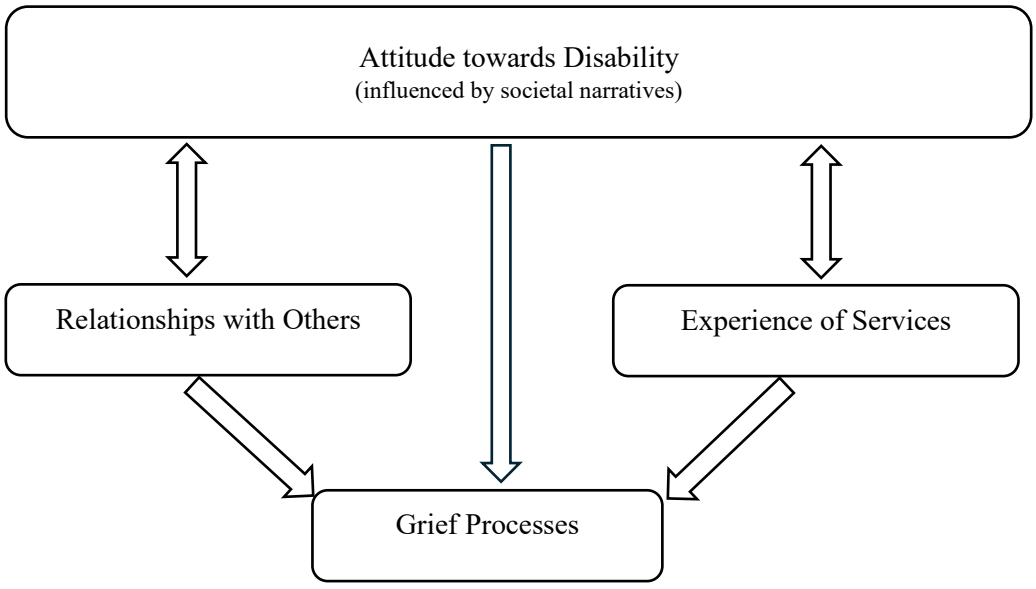
Despite the challenges parents faced when their child was diagnosed, many also spoke of the joys and gratitude they experienced related to their child's learning disability. Parents shared very positive descriptions of their children and of the pleasure that they brought them due to their personalities and at times of progression (Fernández-Ávalos et al., 2020; Davenport, 2020). Some parents also reflected on the positive impact having a child with a learning disability has had on themselves such as it having made them stronger and changed their perspectives on things (Sheehan & Guerin, 2017). Some parents became strong advocates for people with a learning disability, highlighted that those without a learning disability do not necessarily have better lives, and expressed feeling grateful for their experiences (Fernández-Ávalos et al., 2020; Sheehan & Guerin, 2017).

Line of Argument Synthesis

The results of the synthesis suggest that when a child is diagnosed with a learning disability, parents experience a range of different emotions, are required to interact with different professionals, and are influenced by other people's responses to their children which impact their relationships. A line of argument, which combines and interprets the relationship between categories, was developed from the synthesis proposing how parents experience their child being diagnosed with a learning disability. The line of argument for this synthesis is that other people's (including medical staff, family and friends) and parents' own attitudes towards disability (influenced by societal narratives surrounding learning disability), impacts parents' interpretation of the learning disability, their experience of services, and their relationships with others, shaping their overall emotional response to the diagnosis. A model depicting this process is presented in Figure 3. Bidirectional arrows are included to illustrate how attitude towards disability both impacts and is impacted by interactions with others. Despite the ongoing influence of each element, this synthesis suggests some parents reach acceptance and rejoice in their child's learning disability.

Figure 3

Model depicting Line of Argument Synthesis



Discussion

This synthesis provides an overview of how parents experience their child being diagnosed with a learning disability. Four overarching categories were identified: Grief Processes, Experience of Services, Relationships with Others, and Attitude towards Disability. These encapsulate what parents experience and are required to navigate on receiving the diagnosis and thereafter. The line of argument provides a model proposing how these categories interact, to make greater sense of people's experiences. The societal discourse surrounding learning disability is negative, discriminative, and marginalising. This shapes people's attitudes towards those with a learning disability, which was evidenced by parents reports of professionals' negative bias and family, friends, and strangers' judgements, and the parents own emotional response to learning the diagnosis. This impacts parents' experiences of medical and social support, which exacerbates their grief response to the diagnosis. It may also reinforce their fears for their children as they witness the discrimination their children may experience throughout their lives. The hardship of navigating services, the need to focus on shortcomings to access support, and the social exclusion families may face which will be internalised by both parents and children with a learning disability, may impact their own relationships and thus maintains the dominant negative discourse. Also evidenced in this synthesis, this highlights the importance of inclusive and non-discriminative attitudes toward those with a learning disability. Parents shared the beneficial impact of support from trustworthy professionals and having contact with other parents of children with a learning disability, which offered challenge to negative attitudes and normalised their experiences. A lot of parents also expressed reaching acceptance of the learning disability and embracing their child regardless of this, perhaps due to learning the learning disability itself is not the problem, but instead the wider societal perception of disability. The synthesis highlights the need for attitudinal change regarding the

learning disability population, serving to dismantle the dominant discourse oppressing people with a learning disability.

Limitations

The synthesis offers insight into parents' experiences and what impacts this, however, includes limitations to be considered. The studies were conducted in western, educated industrialised, rich, and democratic (WEIRD) countries, reflecting a small percentage of the world's population (Henrich, Heine & Norezayan, 2010). Attitudes towards disability differ across cultures (Florian, 1982), therefore the absence of non-WEIRD countries prevents the results from being generalisable as how parents experience their child being diagnosed with a learning disability will vary across different cultures. Another limitation is that the severity of the child's learning disability across studies was not noted or isolated but instead grouped. This fails to consider nuances between differing levels of learning disability or other coexisting disabilities, which could greatly impact people's experiences of parenting their child and how they anticipate their future on receipt of the learning disability diagnosis. A further possible limitation of the synthesis is that it relies heavily on interpretation and was completed by one researcher due to the resource and time constraints of a Doctoral Clinical Psychology thesis. Researcher bias could therefore be present and unchallenged, shaping the process of the synthesis.

Justification and Implications for the Current Study

As previously noted, there is a paucity of literature that involves people with a learning disability, failing to represent this population and the voice of individuals with a learning disability. Such a dearth has implications for both practice and policymaking

processes, which the perspectives of people with a learning disability are then omitted from. Correspondingly, research has not been completed regarding people with a learning disability's experience of being diagnosed with autism despite the high prevalence of co-occurrence. Individuals with a learning disability and their families experience of autism being observed and assessed is unique from that of the general population due to the learning disability, therefore the impact of receiving an autism diagnosis may be different from that of other populations. The assessment process also involves further navigation of services and the burden of time and resources for both people with a learning disability and learning disability services. It is therefore important to explore whether this is of value to people with a learning disability and their surrounding system. This study therefore aims to explore the impact of receiving an autism diagnosis for adults with a learning disability, to provide representation of autistic people with a learning disability's voice and inform the care this population receives. Family members that support autistic people with a learning disability are included to consider how the autism diagnosis affects the support that they offer to their relative. This synthesis provides a foundation for what people's parents may have experienced when their relative was diagnosed with a learning disability, therefore this was held in mind as to how parents and the adult themselves react and respond to an autism diagnosis during data collection. It has enabled the researcher to be aware of family members potential historical experiences during interviewing. The following chapter details the methodology used to achieve the aim of the project.

Chapter Three: Method

Chapter Overview

This chapter presents a detailed account of how the study was conducted. It begins with a description of the research paradigm which includes the ontological and epistemological stance of the study, the methodology and methods, and a reflexive account regarding the researcher's positionality. The full procedure is then detailed including participant recruitment, data collection, and method of analysis. Following this, ethical considerations, avenues for dissemination, and quality assurance are discussed.

Research Paradigm

A paradigm encapsulates the philosophical foundations that underpin research, providing a lens through which the world is viewed and thus shapes how research is designed (Pretorius, 2024). A number of components make up a research paradigm including ontology, epistemology, methodology, and methods (Scotland, 2012).

Ontological and Epistemological Stance

The ontological and epistemological positioning of the researcher determines the methodology and methods that are adopted in research (Al-Saadi, 2014). Ontology refers to the philosophical assumptions regarding the nature of reality, and epistemology relates to how knowledge about that reality is acquired (Kant, 2014). Ontological perspectives can be understood along the realism–relativism continuum (Harper & Thompson, 2011). At one end is realism; this position proposes that there is an objective single reality which can be observed. At the other end is relativism; this denotes that reality is not fixed but socially constructed through interactions and interpretations. Ontological positioning influences

epistemological assumptions. As realism assumes a single reality, a realist stance typically aligns with positivist epistemology, which proposes that knowledge is generated from observation and measurement (Alharahsheh & Pius, 2020). In contrast, a relativist stance aligns with constructivist epistemology, which views knowledge as co-constructed between people (Alharahsheh & Pius, 2020). There are differing ontological positions along the realism–relativism continuum such as naïve realism, critical realism, historical realism, and relativism (Guba & Lincoln, 1994), and distinguishable epistemological frameworks related to each (Madill et al., 2000). The ontological positioning of this study sits at a midway point on the continuum, adopting a critical realist stance. This reflects that there is an independent reality however people experience this through their own interpretations. This acknowledges the tangible nature of autism and learning disability, but also that people's subjective experiences of these conditions vary depending on their own and other people's perceptions. To explore these subjective interpretations, an interpretivist epistemological approach is adopted which suggests knowledge is acquired through exploring and understanding peoples lived experiences. This directed the methodology that the study employed.

Methodology and Methods

Research methodology denotes the general strategy that the researcher adopts to investigate the topic of interest (Silverman, 1993). This is different from the methods which relate to the specific procedures that are followed, as methodology follows the wider philosophical assumptions that underlie research (Goundar, 2012). Dependent on the philosophical assumptions, quantitative methodology, qualitative methodology, or a combination of the two may be used. For example, if positivist epistemology is employed which favours measurement, a quantitative methodology which utilises numerical data will be adopted. Specific quantitative methods that collect this data will therefore be used such as surveys and experiments (Slater & Hasson, 2025). If constructivist epistemology is employed

which understands knowledge as co-constructed, qualitative methodology is adopted which seeks to explore people's subjective experiences; methods such as interviews, focus groups, and observation may be used (Moriarty, 2011). This study aligns with an interpretivist epistemological stance, which proposes knowledge is acquired through understanding social phenomena in context (Rehman & Alharthi, 2016). To achieve this, a qualitative methodology is followed as this allows researchers to discover meaning and gain information that would be hard to access quantitatively (Starks & Trinidad, 2007; Hoepfl, 1997). This enables autistic people with a learning disability and their family members experiences of autism diagnosis to be explored in order to understand the impact this has had.

As noted earlier, methods are the specific means researchers use to collect data (Rehman & Alharthi, 2016), and these should be those best suited to answer the research questions (Starks & Trinidad, 2007). Interviews are the most commonly used method in qualitative research (Taylor, 2005), particularly those following a semi-structured format (DiCicco-Bloom & Crab-tree, 2006). This allows for flexibility (Kallio et al., 2016) which was deemed important in this study to respond effectively to participants. Alongside flexible interviewing, creative means of data collection such as art-based methods have been used to promote accessibility and inclusion of disabled people in research. Art-based methods have been used to attempt to address power imbalances between researchers and those researched, and include people that do not use verbal language, or explore topics that are difficult to verbalise (Coemans & Hannes, 2017). Art-based methods do however bring challenges, including ethical considerations regarding the privacy and ownership of the work (Dew & Smith, 2025). Additionally, participants may feel pressure regarding their artistic skill, and analysis of the data can be very subjective and rely heavily on researchers' interpretations (Coemans & Hannes, 2017; Dew & Smith, 2025). Due to these challenges as well as the practical constraints of this research, and considering the accessibility needs of eligible

potential participants, this study employed semi-structured interviews. Another approach to support accessibility and inclusion is participatory research, which consists of collaborative development with people representing those that are the focus of research at each step of the process (Vaughn & Jacquez, 2020). Participatory researchers do however have to be conscious of inadvertently silencing people that belong to the researched population with different views and not assume an equalisation of power across members of the research team (Danieli & Woodhams, 2005). As described later in this chapter, the interview guide for participants with a learning disability was developed in consultation with experts by experience to ensure accessibility. As the other steps of the research process were not completely collaboratively due to time constraints, this study cannot be considered participatory research.

Reflexivity and Positionality

Qualitative research is inherently subjective; participants describe their experiences which researchers interpret, both through their own subjective lens. As researcher participation is a significant aspect of research, analysis of their positioning is required to identify the influence this has on decision making and interpretations (Olmos-Vega et al., 2023). This can be considered through practicing personal reflexivity throughout the entirety of the research. Personal reflexivity within research is a continuous process of examining and challenging the researchers' perspectives and assumptions, to enhance the trustworthiness and quality of the research (Barrett et al., 2020). As part of this process, researchers can consider the position that they hold within and beyond the research to understand the effect of their personal and professional characteristics (Wilson et al., 2022). The remainder of this section will be written in first person to convey my position in relation to the study.

I was diagnosed with a neurodevelopmental condition during adulthood, which prompted me to reconsider some of the interpretations that I held regarding my identity. This led to my interest in how later diagnosis of neurodevelopmental conditions impacts people's understanding and narratives of themselves. At times I find this diagnosis helpful, however I can also feel sceptical regarding the existence of medical categorisations of neurological variance, due to concerns that being labelled 'neuroatypical' can be pathologizing. I fear this can limit what society views as 'normal' when in fact everyone is neurodiverse. This is reinforced systemically as often services cannot be accessed unless a diagnosis has been given, as opposed to being needs led.

I am interested in how this impacts the learning disability population, in which co-occurring neurodevelopmental conditions are common. It may be less possible for people with a learning disability to reject negative consequences of diagnosis due to necessary reliance on healthcare systems and power differentials in operation. As someone who feels that at times my neurodivergence has been misunderstood, I feel a duty as someone without a learning disability, to support the learning disability population to increase equity. As a population that commonly accesses more social support, I felt it was important to include family members within my research but felt it was essential to include people with a learning disability in view of the lack of existing research including this population.

As I have been diagnosed with a neurodevelopmental condition, but do not have a learning disability, I consider myself simultaneously an 'insider' and an 'outsider' within this research. An insider researcher shares key attributes with the participants in their research, whereas an outsider does not (Braun & Clark, 2013). There can be advantages and disadvantages of both positions; for example, insider status may enhance researchers' understanding, however outsider status may support objectivity (Savvides et al., 2014). Positionality is also multi-dimensional as my perceived positionality, participants perception

of my positionality, and my actual positionality co-exist (Bukamal, 2022). As I view my neurodevelopmental condition as invisible, I assume participants view me as an outsider in which there are also pros and cons. Sharing group membership can enable participants to feel more trusting of researchers which supports openness, however they may also assume similarity therefore explain their experiences in less depth (Dwyer & Buckle, 2009). As well as considering neurodivergence, I used the Social Graces model (Burnham, 1993, and Roper-Hall, 1998) to help me reflect on the influence I may have during data collection. I am a white British, cis-gendered, able-bodied person that has been able to access education, and within my role as interviewer I got to ask the questions. To support mitigation of the power I held during interviewing, alongside following ethical guidelines and providing accessible materials, I ensured participants had the opportunity to contribute and challenge as much as desired and ask me questions in return. I understand this is dependent on their comfort levels; therefore I attempted to foster this throughout.

To support my personal reflexivity including how my position influences my interpretations throughout the project, I kept a reflective log as recommended by Gurr et al. (2024). I utilised this following each interview and research meeting and discussed my reflections in research supervision. I also considered biases I felt at increased risk of. Initially, due to my own opposing opinions regarding diagnoses of neurodevelopmental conditions, I thought I was relatively neutral; however, during interviewing I recognised that I held an internal desire for participants to reject diagnostic labelling, which many did not. I was mindful of this during data analysis in order to neutralise its impact. As well as the impact of the researcher, personal reflexivity should also include the impact of the research on the research team (Finefter-Rosenbluh, 2017). I included this within my reflective log and outline some of my reflections in the self-reflexivity section in Chapter Five.

Study Setting

The study was a single-centre study hosted by an NHS Trust in the East of England that provides learning disability services. The research site was selected as it delivers care for adults with a learning disability and their family members which includes the completion of autism assessments.

Consultation with Experts by Experience

As stated by the National Institute for Health and Care Research (NIHR; 2021), involving members of the public within research regarding health and social care services is now expected, as this can improve the quality and relevance of the research and may have consequential effects for those using services. One way this is done is through collaborating with experts by experience. Experts by experience are people that have recently used, or support others that use, services (Care & Quality Commission [CQC], 2025). Within the current research project, experts by experience may consist of people with a learning disability, autistic people, and people who provide support to autistic people and/or people with a learning disability such as family and friends. Consulting with people with a learning disability felt particularly pertinent as the learning disability population is underrepresented in research, and co-producing materials to be used within the project supported their accessibility, aiding both participant experience and the data collection process. To achieve this, the researcher attended an NHS led service user involvement group that meets regularly to consider ways to improve learning disability services; this is attended by people that currently or have historically accessed learning disability services and staff members working within them. The project was introduced and the first draft of the easy-read interview guide for participants with a learning disability was presented for feedback. Potential improvements

were discussed and subsequent amendments were made. Following this the researcher attended the next meeting to re-present the interview guide to confirm the final draft. The interview questions, the options of answers, and the presentation of the schedule were co-produced by the researcher, people with a learning disability, and staff working in learning disability services.

Procedure

Promotion

To begin promotion of the study the researcher attended an NHS service meeting and presented the project to NHS staff, as clinicians acted as 'gatekeepers' for recruitment, acting to link the researcher to potential participants. There can be advantages and disadvantages to using gatekeepers in research. For example, they may enable access to potential participants when this is otherwise not possible (Clark, 2012), however they may select particular people which could lead to a biased sample (Clark, 2010). In addition, willingness to take part could be influenced by potential participants perceptions of the gatekeeper and their relationship with them (Riese, 2019). The researcher presented the aims of the project and the inclusion and exclusion criteria for participants. Study posters were also shown to clinicians to support their knowledge of the study to aid recruitment. Following this meeting the researcher had ongoing communication with NHS staff regarding recruitment via email, and as part of this the study posters were sent to staff to display on Trust sites and to give to potential participants to advertise the study.

Recruitment

Recruitment can be active in which eligible participants are approached, or passive where research is advertised to communities using methods such as flyers, posters, and media

(Fleming et al., 2015). This study used both approaches as patients were contacted directly, and posters were sent to staff to display on Trust sites. NHS staff were asked to inform eligible patients and their family members of the research. If they were interested in participation, consent was obtained from them to be contacted by the researcher, and their contact details were shared. Potential participants were then contacted to discuss the study, and on agreement were sent participant information sheets. Recruitment can be influenced by researchers' ability to build rapport with potential participants (Negrin et al., 2022), therefore the researcher endeavoured to achieve this when making initial contact. If patients or their family members were to contact the researcher directly via poster advertisement, the researcher planned to discuss their eligibility with the clinicians involved in their care prior to sharing participant information sheets; however, this did not occur.

Data Collection

As participants agreed to take part, their preferred interview format was discussed, and interviews were arranged at a mutually convenient time. If adults with a learning disability and their family members both agreed to participate, they were asked if they wished to be interviewed together or separately. Interview guides were utilised during interviews and participants were offered a copy of these ahead of time via email to allow them time to consider and plan their answers, as well as at the start of interviews. This was to support participants that may benefit from additional processing time to consider their responses, as well as reduce anxiety due to increasing predictability. This may have also helped family members consider information that they wish to share or not share including topics that might be sensitive. Interviews were completed in the preferred format and were recorded using Microsoft Teams; Teams meetings were set up to enable recording whether interviews were completed online or in person.

Pilot work, in which planned research protocols are tested prior to studies taking place, can be used to identify potential difficulties (Hassan et al., 2006). Completing pilot interviews allows schedules to be vetted and amended, enabling higher quality data to be collected (Castillo-Montoya, 2016). The first two interviews were therefore considered as pilot runs, following which the researcher considered any amendments that needed to be made. As opposed to resulting in modifications to the interview guides, the pilot interviews gave the researcher practice in navigating the data collection process. Learnings from this included ensuring they reorientated conversation back to topic if participants moved away and recentring participants with a learning disability during their interview if family members contributed. As alternations were not made to the interview guides, pilot interviews did not carry implications for the ethical review process. As the participants were eligible and quality data was collected, data from the pilot interviews was included in the final dataset.

Participants

All participants were recruited through NHS learning disability services. Purposive sampling was employed as participants were selected based on their experiences. Participants could be individuals with a learning disability, or a family member(s), or an individual with a learning disability and their family member(s). The researcher aimed to recruit a mix of individuals with a learning disability and family members to ensure both populations experiences were included.

Inclusion and Exclusion Criteria

Patients and/or family members had to meet criteria to be eligible to participate. Inclusion criteria consisted of being over 18 years of age and having or being the family member of someone with a learning disability that has received a diagnosis of autism. The

individual being open to the learning disability service was taken as evidence of them having a learning disability, as this would have been assessed by clinicians at initial referral. Close family friends or support staff could be included at participant discretion. The autism diagnosis must have been received during adulthood (over the age of 18). It must have been a minimum of one month since the autism diagnosis was received to allow participants time to have processed the diagnosis, and up to a maximum of 10 years since diagnosis to support their memory recall. Participants must have been deemed to have capacity to consent to take part in the research by clinicians involved their care. Exclusion criteria consisted of current involvement in an active safeguarding investigation, acute mental or physical illness, and if deemed unable to consent to take part.

Materials

Posters

Two posters outlining the study were developed to provide information to potential participants and to advertise for recruitment. One poster was addressed to adults with a learning disability which is displayed in Appendix A, and the other poster was addressed to family members which can be found in Appendix B.

Interview Guides

Two interview guides were developed to address the research aims and support interviewing. One was developed for people with a learning disability, and another was developed for family members. When being interviewed together, the participant with a learning disability was asked questions first, followed by the family member(s), therefore both guides were used. The interview guide for adults with a learning disability came in easy-read format and was offered to participants both ahead of interviews and during interviews.

As previously described, this was developed in consultation with experts by experience to support accessibility. The content included questions regarding the initiation and experience of the autism assessment, how they felt on learning they have autism, what changes diagnosis has made, and if they would recommend assessment to others. On feedback from experts by experience, possible answers participants could select were included on the guide. The guide can be found in Appendix C. The interview guide for family members similarly asked participants who initiated the assessment, how they felt when their relative was diagnosed, the impact of the diagnosis, and the consequences. This guide can be found in Appendix D.

Data Analysis

The analytic procedure in research can be approached in two main ways: deductive or inductive reasoning. Deductive reasoning adopts a theory or hypothesis and utilises study findings to test this, whereas inductive reasoning develops theories or concepts based on study findings (Yuwono & Rachmawati, 2023). Inductive reasoning is more commonly used in qualitative research (Lathlean, 2006). As this allows for greater exploration of under researched topics (Yuwono & Rachmawati, 2023) and therefore supports greater understanding, this study adopted an inductive approach.

There are a variety of types of qualitative data analysis including but not limited to content analysis, discourse analysis, thematic analysis, and grounded theory (Graue, 2015; Williamson et al., 2018). Transcription is often one of the first steps of data analysis and is a central practice across many forms of qualitative research (Davidson, 2009), therefore is this considered first.

Transcription

Details of transcription are often not included in qualitative research, yet literature has emphasised the need to be explicit about the transcription process (Davidson, 2009). During interviews, the built-in transcription function in Microsoft Teams was used whilst interviews were being recorded. On completion, transcripts were downloaded into Microsoft Word documents and any names that were mentioned were removed. Following this the researcher listened to each recording and simultaneously edited the transcription to produce a full verbatim account of each interview. Transcription can be naturalised in which all details are included as accurately as possible, or denaturalised in which non-verbal communication, stutters, and pauses are removed (Oliver et al., 2005). As complete and accurate accounts have been deemed to be the highest quality of transcription (Hagens et al., 2009), a naturalised approach was adopted. To correct potential errors and enhance their quality, transcripts can be checked with participants (Mero-Jaffe, 2011). Due to the communication needs of the participants and the practical constraints of this project, the researcher was unable to achieve this. Braun and Clark (2006) and Davidson (2009) recommend that transcription is completed as soon as possible after interviewing, to support accuracy and familiarity. Whilst managing time restraints, transcription was completed as possible during the data collection phase to reduce the time spent between interviews and data analysis. Interview recordings were deleted on completion of each transcript, and transcripts remained as Word documents for further analysis.

The transcription process itself is analytic, as it requires interpretation by the transcriber (Bailey, 2008). When researchers undertake this process themselves, it facilitates early familiarisation with the data and may enhance their understanding more than if transcription is outsourced (Braun & Clarke, 2006). All the transcripts in this study were completed by the researcher.

Analytic Plan

The type of data analysis that is employed is influenced by the researcher's theoretical positioning and the aims of the study (Mezmir, 2020; Liamputtong, 2009). One of the most commonly used forms of analysis in social science research is thematic analysis (TA), which entails identifying patterns across data through constructing and interpreting themes (Christou, 2022). Unlike some forms of qualitative data analysis, TA can be used across a range of epistemologies and research questions (Nowell et al., 2017) as it is not tied to a particular philosophical framework (Campbell et al., 2021). Consequently it can be used in research situated at different points along the realism-relativism continuum. Coming from a critical realist position, TA was deemed appropriate for this study as it can acknowledge the presence of an independent reality, which individual's experience through their own interpretations. Additionally, TA is regarded as an accessible form of analysis and can be learned with relative ease, making it suitable for both developing and experienced researchers (King, 2004; Braun & Clarke, 2006). As Braun and Clarke (2006; 2019) have developed a six-step process for completing TA, researchers are provided with direction throughout the analytic process (Campbell et al., 2021), and are required to be well-structured (King, 2004).

Braun and Clarke (2018) describe TA as an umbrella term, as different approaches can be taken when practicing TA. They have clustered approaches into three variations: coding reliability, codebook, and reflexive (Braun and Clarke, 2019). Reflexive thematic analysis (RTA; Braun & Clarke, 2019) was deemed most suitable for the current study as this acknowledges the inherent role of the researcher influencing the analytic process, adhering to the values of qualitative research. This was even more important due to the insider outsider status of the researcher.

Reflexive Thematic Analysis

Braun and Clarke's (2006) step-by-step guide was followed which incorporates six phases:

Phase 1: Familiarisation of the data. This consisted of immersion into the data by first-hand transcribing, repeated reading of the transcripts, and note taking. This was completed during both the data collection and data analysis phase.

Phase 2: Generating initial codes. This incorporated coding the entire data set working through each transcript, including both semantic and latent codes. Semantic codes consist of explicit data content written as vocalised by participants, whereas latent codes go beyond description identifying underlying meaning (Byrne, 2022). Both forms of coding were completed without the prioritisation of either. Initially codes were noted directly on to each transcript using the comment function on Microsoft Word, then all codes were transferred to Microsoft Excel to enable organisation.

Phase 3: Searching for themes. This involved analysing relationships between codes and organising them into themes including overarching themes and corresponding subthemes. Separate Microsoft Excel sheets were made to group related codes before organising them into themes then subthemes.

Phase 4: Reviewing themes: This consisted of reviewing each theme and subtheme, ensuring each corresponds and relates to the whole dataset. This was assisted by the generation of the thematic map reflecting how themes and subthemes were connected.

Phase 5: Defining and naming themes. This involved the refinement of themes and subthemes, appropriately defining each and ensuring they relate coherently. The names of each theme and subtheme were continuously revised to ensure comprehension and accuracy.

Phase 6: Producing the write-up. Once data analysis was complete, extracts illustrating each theme and subtheme were compiled into Microsoft Word documents, to enable identification of the most appropriate quotations. Draft versions of the results were then written until completion.

To support reflexivity throughout data analysis, the researcher kept a reflective log detailing their reflections regarding their positioning in relation to the data and their relationship to the analytic process to increase awareness of their personal contributions. These were also discussed with the research supervisors.

Ethical Considerations

At all stages of the research process, scientific research must adhere to ethical principles designed to protect human dignity and respect autonomy (Taquette et al., 2022). Qualitative research includes additional considerations as researchers play an active role during data collection rather than being passive observers (Peter, 2015). Applicable ethical considerations are addressed below.

Ethical Approval

As outlined by the British Psychological Society's (BPS) code of human research ethics (2021), if research involves NHS patients or their relatives or carers, an external ethical review must be completed by an NHS Research Ethics Committee (REC), provided by the Health Research Authority (HRA). The process for this was undertaken and following the review, a favourable opinion was granted from the REC and HRA; evidence of this is displayed in Appendix E and Appendix F. Following this, as per HRA requirements, the NHS Trusts' Research and Development department conducted a Capacity and Capability assessment and granted approval for the research to commence in the designated site;

documentation for this can be found in Appendix G. Ethical approval was also obtained from the University of Essex which is presented in Appendix H. All necessary rules and regulations in accordance with REC, HRA and University guidelines were followed.

Informed Consent

Only adults with a learning disability that were deemed to have capacity to consent to take part in the research were approached by NHS staff regarding the study. If potential participants were to have contacted the researcher directly through poster advertisement, the researcher planned to consult with their allocated NHS clinician to ensure they had capacity to consent, however this did not occur. Following this, in line with the Mental Capacity Act (2005) and the BPS's code of human research ethics (2021), participants were presumed to have capacity to consent unless there was evidence to suggest otherwise.

When recruited via NHS staff, consent was granted from potential participants for the researcher to contact them regarding the study. They were then provided with information sheets detailing the purpose of the study and what participation would involve. Two different information sheets were developed; an easy-read version for adults with a learning disability, and a non-easy-read version for family members without a learning disability, to ensure accessibility. These can be found in Appendix I and Appendix J. Potential participants were given opportunities to ask questions and time to consider participation. When participants agreed to take part, formal consent was obtained through the completion of consent forms. Both easy-read and non-easy-read versions of the consent form were developed; these are presented in Appendix K and Appendix L. Both information sheets and consent forms included that participation was voluntary, and that their decision to take part or not take part would not affect the care that they receive from the NHS learning disability service. They also included that participants could withdraw from the study if they no longer wanted to take

part, and that their data could be extracted unless their anonymised responses had already been merged with the larger dataset. If participants advised they were unable to complete written consent forms when interviews were completed online, verbal consent was obtained at the start of interviews. The researcher confirmed that participants understood the information they were given and that any questions had been answered prior to the commencement of interviews.

Confidentiality

Within the information sheet for family members and at the start of the interviews, participants were informed of the limits of confidentiality, including that confidentiality would be breached if concerns regarding the safety and wellbeing of themselves or others were raised during interviews. Should this occur, the researcher would discuss their concerns with their project supervisors in the first instance and if necessary, share information with the NHS staff involved in the participants' care who would follow appropriate Trust policies and procedures.

Anonymity

Participants names were not used to ensure anonymity. As a qualitative study, the results chapter and any potential future publications include direct quotations from participants; all names have been omitted.

Data Storage

Interview recordings were deleted following transcription, and all electronic data was stored on Box, a secure cloud-based, password-protected system provided by the researcher's educational institution. Data was processed in accordance with the data protection law and will comply with the General Data Protection Regulations (EU) (GDPR) from the Data Protection Act (2018).

Participant Distress

It was possible that participants could experience difficult emotions during interviews. To account for this, participants were informed that interviews could be terminated at any point on request, and information regarding support services was readily available if required. The researcher also planned to offer to contact the NHS staff members involved in their or their relatives care from the NHS learning disability service on participants behalf should this be desired. Should participants express dissatisfaction regarding their experience of services, the researcher had information for the NHS Trusts Patient Advice and Liaison Service to provide.

Researcher Wellbeing

No distress was anticipated for the researcher, and regular research supervision was arranged in which this could be discussed if required. To ensure the researchers safety when completing interviews at participants homes, the NHS Trusts lone working procedures were followed which included informing NHS staff of the participant(s), date, time, and venue of interviews.

Dissemination Plan

Dissemination is a planned process for communicating research findings to target audiences, in order to influence wider policy and practice (Wilson et al., 2010). A plan was developed to disseminate the study findings in several ways.

This thesis will be available on the University of Essex Research Repository following the completion of the Doctorate in Clinical Psychology. All participants were offered a written, accessible summary of the findings upon completion of the project. A

summary of the research will be shared with appropriate NHS services including the recruiting learning disability service. The researcher intends to submit the research for publication in relevant academic journals such as the Journal of Learning Disabilities and the Journal of Autism and Developmental Disorders. On opportunity the research will also be shared with organisations such as the BPS and the appropriate faculties such as the Division of Clinical Psychology Faculty for People With Intellectual Disabilities, and at relevant conferences such as the Faculty for People with Intellectual Disabilities Annual Conference (BPS), the Annual International Academy for Research in Learning Disabilities conference, and the British Institute of Learning Disabilities (BILD) conference.

Quality Assurance

The researcher aimed to produce high quality research that was meaningful and valid. Criteria have been developed that researchers can use to judge the quality of research. For example, Guba and Lincoln (1994) proposed that trustworthiness is based on credibility, transferability, dependability, and confirmability. To support these concepts and ensure overall research quality, the researcher adopted several processes throughout the study. An audit trail of all research activity including research meetings, supervision, and interviews was kept; rigorous documentation supports dependability and confirmability, as well as transparency (Korstjens & Moser, 2018; Ahmed, 2024). As is essential in qualitative research, researchers require high levels of self-awareness regarding their own role (Mauthner & Doucet, 2003). As previously stated, to support reflexivity a reflective log was kept noting learnings and thought processes regarding the researcher's influence; this was particularly used straight after interviews. Regular reflexive journalling can support confirmability (Ahmed, 2024). The researcher also had regular research supervision to discuss reflections

and processes, plan next steps, and access guidance. Consulting with experts by experience helped ensure the interview guide was accessible for people with a learning disability, improving the interview experience and supporting validity. The researcher also endeavoured to make participants feel comfortable and used general conversation and introduced the project at the start of interviews to build rapport and address any questions. The researcher also checked that their understanding of participants answers were accurate during interviews with participants and sought feedback regarding their experience at the end. All participants were offered a summary of the final results and the researcher ensured they were able to contact them if they had any questions or concerns at a later date. Braun and Clark's (2020) tool for evaluating TA was also consulted with during data analysis and write up to support quality. A discussion of the strengths and limitations of the study is included in Chapter Five.

Chapter Four: Results

Chapter Overview

This chapters presents the results of the study. It begins with a description of the study sample, which is followed by a section on methodological considerations regarding data collection processes. The results of the RTA are then displayed which consists of five themes and 13 corresponding subthemes.

Sample

A total of 18 interviews were conducted comprising a mix and total of 32 participants. Data saturation, a point in qualitative data collection where continued interviewing produces no new information, was reached in the latter stages of interviewing (Guest et al., 2020). Three interviews were completed with an autistic individual alone, and four interviews were completed with family members alone, three with one parent and one with two parents. There were 11 interviews attended by both autistic individuals and their family member/s or support staff together. This consisted of one interview with both parents, eight with one parent, one with a sibling, and one with a support worker. The obtained sample aligns with maximum variation sampling, a sampling strategy used in qualitative research in which different types of participants are purposely recruited (Suri, 2011). The intention of achieving a diverse sample of participants is to access different experiences to gain a holistic understanding of the phenomenon under study (Suri, 2011). The interview format aligned with participant preference; five were conducted online, and 13 were conducted in person including a mix of at participants homes and at a NHS clinic site. More autistic males than autistic females, and more female family members than male family members took part. Most autistic individuals were between age 20-29 and most family members were aged 60-69. All adults that had

received a diagnosis of autism had been assessed through an NHS community learning disability service. The majority of autistic participants had been diagnosed within the last 6 months. The characteristics of the sample are presented in Table 5.

For some participants, contact with the NHS service coincided with the COVID-19 pandemic, the global outbreak of the infectious disease coronavirus (World Health Organisation, n.d.). To manage the spread of coronavirus, three national lockdowns which minimised social contact, closed non-essential businesses, and restricted essential services such as the NHS, were imposed in England across 2020 and early 2021 (House of Commons Library, 2021). The pandemic placed unprecedented demands on acute care services, which triggered reorganisation of services and staff, and subsequent disruptions to routine care (Propper et al., 2020). Given that all participants' autism assessments were completed by an NHS service, consideration was given to how COVID-19 may have impacted their experiences. Three participants that were family members suggested the pandemic prompted them to access support for their relative due to the disruption this caused. Their relative experienced difficulties in light of this which may have contributed to autism being considered. Two of these participants referred to how it took a long time for the autism assessments to be completed, possibly due to how the pandemic affected the ability of services to offer appointments. Two other participants referred to the use of video appointments; a substitute many services utilised to minimise contact to manage COVID-19. One family member commented on the importance of autism assessments being completed in person to ensure accurate assessment, and one of the autistic participants shared their preference for seeing people in person. The pandemic appeared to impact a few participants' experiences, including possibly contributing to autism being identified, and the time it took for assessments to be completed. It did not appear to affect post-diagnostic processes.

Table 5

Sample Characteristics

Demographic			Frequency
Participant/s			
Autistic Person alone			**3**
Autistic Person and Other/s			**11**
	Mother and Father		1
	Mother		9
	Father		1
	Sibling		1
	Support Worker		1
Family Member/s alone			**4**
	Mother		3
	Mother and Father		1
Gender			
	Autistic Person		
		Female	6
		Male	7
		Trans male	1
	Family Member		
		Female	13
		Male	4
	Support Worker		
		Female	1
Age in years			
	Autistic Person		
		20-29	7
		30-39	3
		40-49	3
		50-59	1
	Family Member		
		30-39	1
		40-49	2
		50-59	4
		60-69	6
		70-79	3
		80-89	1
	Support Worker		
		40-49	1
Time since Diagnosis			
	0-6 months		8
	7-12 months		2
	1-1.5 years		4
	1.5-2 years		0
	2-2.5 years		1
	2.5-3 years		2
	3-3.5 years		1

Note. One participant interviewed alone and then joined their family member during their interview; this has been recorded as one interview under autistic person alone.

Methodological Considerations

As some interviews included more than one participant, and there were different interview guides for autistic people with a learning disability and family members, the researcher considered how best to conduct interviews. There is little literature regarding interviewing families as a group (Eggenberger & Nelms, 2007), however the researcher considered potential issues that could arise from the presence of multiple people, such as the influence they could have on each other or if participants disagreed.

To begin with, related participants were given the choice of individual or joint interviews, a recommendation Voltelen et al. (2018) make when considering ethical issues of family interviewing. It is also important that the researcher is not seen to favour particular interviewees (Eggenberger & Nelms, 2007; Voltelen et al., 2018), therefore the researcher ensured they actively engaged with every participant by developing rapport at the start and using appropriate eye contact and active listening during interviews. This was deemed particularly important when a participant had a learning disability due to the power differentials present, and the researcher ensured they attempted to mitigate this throughout the data collection process. If interviewees comment on the same thing, it is important space is given for different points of view to prevent the disempowerment of any interviewee (Voltelen et al., 2018). Therefore, if during interviewing a family member answered on behalf of or offered suggestions of answers for a participant with a learning disability, the researcher checked that this was accurate for the participant with a learning disability. There is also literature that suggests people with a learning disability are at greater risk of acquiescence, a tendency to agree with others regardless of content (Sigelman et al., 1981). This has been deemed a potential difficulty when interviewing people with a learning disability as it impacts the validity of findings, however researchers can act to reduce acquiescence (Finlay & Lyons, 2002). It is more likely to occur when someone does not know the answer to a

question, therefore researchers can ensure questions and interview materials are accessible, and that expressing uncertainty is acceptable (Finlay & Lyons, 2002). Similarly, echolalia, a phenomenon in which people imitate the speech of others, is more common in autistic people (Ryan et al. 2024), therefore the researcher looked out for this. At the start of interviews, the researcher explained there are no right or wrong answers, including if there is no answer at all. Some literature on acquiescence in the learning disability population frames this as driven by people with a learning disability, whereas it may be due to others failing to meet their communication needs preventing accessibility. It is also important to be aware that people can unintentionally prevent people with a learning disability from participating equally in conversation. Hutcheon et al. (2017) found that caregivers of an individual with a developmental disability could speak over or for, interrupt and 'correct' them. They highlight that adults with a developmental disability carry agency through steering and resisting in interactions with others (Hutcheon et al., 2017). To try and reduce the power imbalance and support participants with a learning disability to share their stories, the researcher structured the interview by explaining they were going to ask questions to the participant with a learning disability first, interviewed them first, and then invited them to contribute throughout their family member's interview at any point. If a family member contributed whilst the participant with a learning disability was answering, the researcher checked their contribution was accurate for the participant with a learning disability.

Alongside considering potential issues during interviewing prior to data collection starting, the researcher utilised their reflective log after each interview and made appropriate subsequent amendments. For example, the researcher identified that they needed to amend the pace of questioning to suit the participant and utilise the easy-read interview guide which displays possible answers to questions with participants sooner when this would be helpful. The researcher also noted family members discomfort often expressed through laughter if

their autistic relative changed the topic of the conversation during interviewing and ensured they demonstrated their ease of this by responding to participants comments before manoeuvring the conversation back to the interview topic as appropriate. Following an interview in which a participant demonstrated high energy, the researcher brought focus tools, also known as fidget toys, to the remaining in person interviews and offered these to participants as a way to support comfort. Focus tools can help people manage sensory issues, anxiety, and attention by channelling and expelling energy into a physical object (Biel, 2017) and were utilised by several participants once offered. The researcher also noted their own initial frustrations regarding the length of interviews, as they believed interviews should be approximately an hour each and some were shorter than this. On reflection, the researcher considered that the length of interviews may be reflective of participants communication styles, and that their expectation was based on ableist assumptions. There is an expectation that interviews are uninterrupted, detailed stories, which excludes a lot of the population (Kirkevold & Bergland, 2007). Hosking (2024) shares how ableism in research creates barriers for disabled people and can bias the research process and results. Through reflecting on this the researcher was able to let go of these expectations and thus allow interviews to come to a natural end instead of attempting to extend the length, enhancing the experience for participants. The researcher also reflected on how, as questions were orientated to autism diagnosis, they may unintentionally reduce the identity of an autistic individual to their diagnosis and/or medicalise their characteristics. To counteract this, the researcher acknowledged that the focus of interviews was on autism diagnosis and tried to explore this in a neutral and curious way. Further important reflections included that often family members expressed surprise at how much their autistic relative had shared during interviewing and commented on their own learning from the experience. The researcher also

noted that often participants held limited knowledge specifically regarding autism, which carries implications for clinical services. These are discussed in Chapter Five.

Findings

As detailed in Chapter Three (RTA section), Braun and Clark's (2006) six step guide to RTA was followed and implemented. As part of analysis the decision was made to combine autistic individuals and family members data as opposed to separating this, due to the commonality across data. The RTA resulted in the construction of five themes and 13 corresponding subthemes, which are displayed in Table 6. Figure 4 presents the thematic map that was constructed during the analytic process, demonstrating the different connections between themes and subthemes. The researcher additionally noted suggestions and recommendations that participants gave for services and people that support autistic people. These were not included within the RTA as they do not align with the research aims of this thesis, however, the researcher felt these were important to include and to convey to the recruitment site. These are displayed in Appendix M.

Table 6

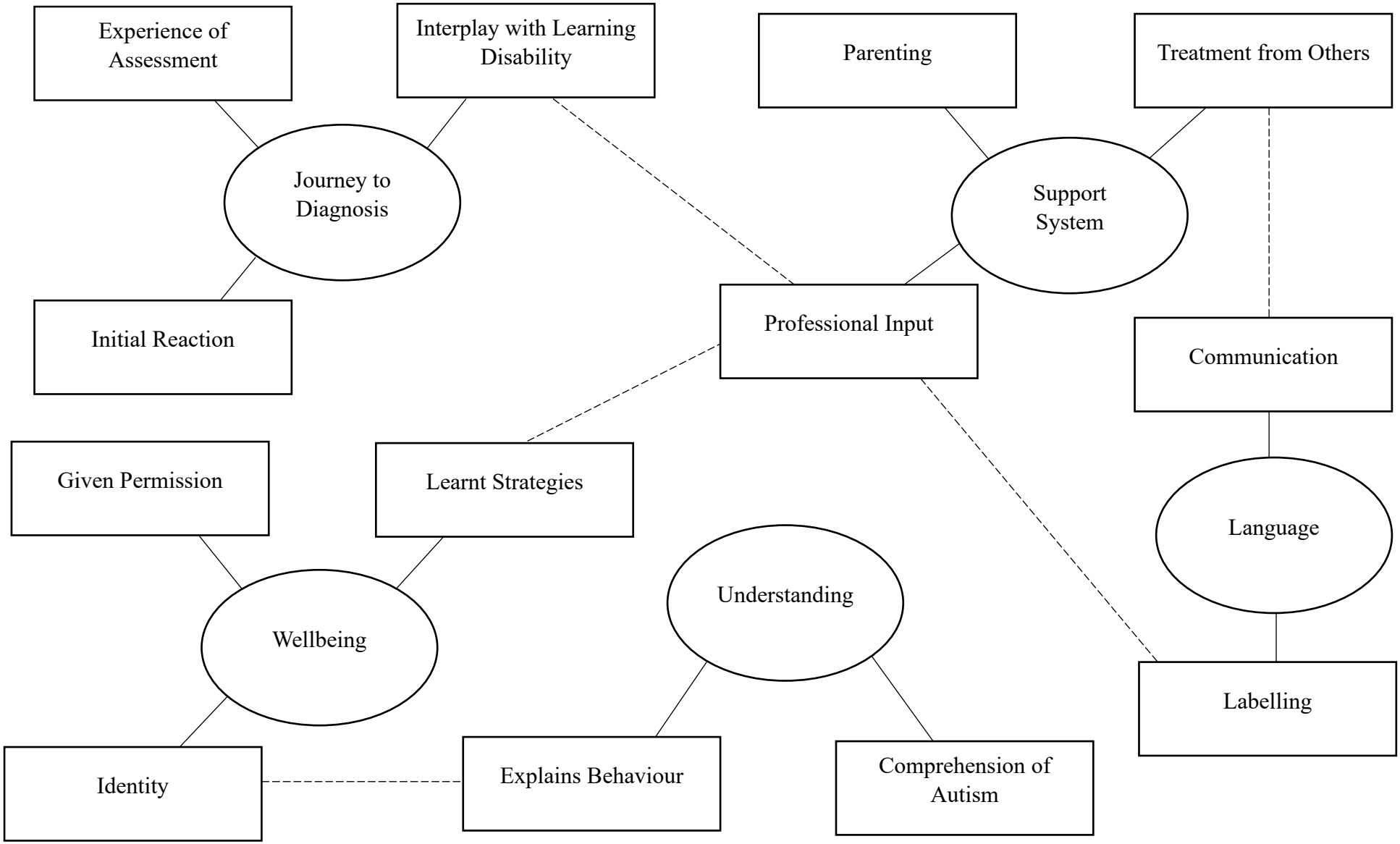
Themes and Subthemes

Theme	Subtheme
Journey to Diagnosis	Interplay with Learning Disability
	Experience of Assessment
	Initial Reaction
Understanding	Explains Behaviour
	Comprehension of Autism
Wellbeing	Identity
	Given Permission
	Learnt Strategies
Support System	Professional Input
	Treatment from Others
	Parenting
Language	Labelling
	Communication

To ensure rigour the researcher studiously implemented each step of RTA and utilised Braun and Clark's (2006) 15-point checklist of criteria for good TA. Due to project constraints the RTA was completed solely by the researcher leaving analysis open to researcher bias, however the researcher ensured to utilise their reflective log to actively consider and neutralise their assumptions. Consideration was also taken regarding how best to present the findings of the RTA. The format of this thesis follows APA style (7th edition; American Psychological Association, 2020) which suggests that block quotations from research participants should be greater than 40 words. Often autistic participants and family members spoke in shorter sentences, therefore in order to align with the participants in this study and to most clearly present the findings, quotations under 40 words have been included as block quotations when demonstrating themes.

Figure 4

Thematic Map displaying Themes (ovals) and Subthemes (rectangles). Solid lines represent connections between themes and related subthemes, and dotted lines represent semantic connections between themes and subthemes.



Theme One: Journey to Diagnosis

The theme Journey to Diagnosis relates to participants experiences of autism being identified, assessed, and diagnosed. This incorporates autistic adults' earlier life experiences including the influence of learning disability, the autism assessment itself, and how participants received the diagnosis, from both autistic peoples and their family members perspectives.

Subtheme One: Interplay with Learning Disability

As all autistic participants were diagnosed in adulthood, the timing and age at which the diagnosis was received was reflected on, as well as how having a learning disability influenced this. Most autistic participants felt it would have been *"easier if I got diagnosed earlier in life"*, for several reasons, including believing *"there would have been more help"* and to have a better understanding of autism:

"I would have found it a bit easier if I got diagnosed earlier in life because that would have made me understand more of myself." (Participant 5)

Most participants that were family members similarly shared it would be *"better earlier for parents"*, with one stating:

"We should have had it diagnosed earlier…We could have, planned more, we could have, erm, it would have been more integrated into our lives if we'd known about it when we could have helped her more as a child and planned more what to do and probably researched it more." (Participant 12)

When considering why autism had not been diagnosed sooner, some family members reflected on the impact of the learning disability with the consensus being *"the learning disability complicated it"* and can *"overcloud it"*. They shared experiences of diagnostic overshadowing, in which their family member's behaviour was attributed to their learning disability:

"It was just accepted as, it's accepted, you know this is how someone like that might behave really." (Participant 22)

One parent expressed they tried to counteract diagnostic overshadowing but weren't listened to:

"Even when we were telling them see, they should look beyond, they should look beyond, but no." (Participant 7)

Similarly, an autistic participant who felt let down that their autism wasn't picked up sooner stated:

"people will look at a child like me and say, you know, she's a bit slow of learning and then just think she's just got a learning disability and that's it. So, they don't look." (Participant 24)

There was however variation in how the interplay with learning disability was experienced by family members. For some, age at autism diagnosis didn't matter so much due to the influence of the learning disability. One parent expressed their child was *"getting all the support that they needed"* already and *"went to a special needs school anyway"*, reflecting that the presence of the learning disability facilitated specialist support for the child regardless of their autism diagnosis. This subtheme highlights the nuanced experiences autistic people with a learning disability can have, due to how these conditions can interact which influences the identification and support needs of each condition.

Subtheme Two: Experience of Assessment

For the majority of participants, a clinician from the community learning disability service suggested that they or their family member was put forward for an autism assessment, including nurses, psychologists, psychiatrists, and speech and language therapists. Family members were the second most common to initiate assessment. For most this was "*to try and explain what was going on with me"* and understand *"my behaviour"*, and many shared knowing *"something else was there"* before the assessment took place. All autistic participants were happy to be assessed, with one explaining:

"I needed some answers…I didn't know why I freaked out when it didn't, become set or if something were in my plan, what I planned in my head, I didn't understand why I freaked out or kicked off or have a full blind meltdown." (Participant 25)

Commonly assessments were described as *"OK"* and *"alright"*, before participants expanded on how they experienced the process. A few family members commented on the length of time it took for the assessment to take place following autism first being mentioned,

describing this as *"so long"* which for one family felt *"a bit unacceptable"*. Reporting on the assessment itself, several autistic participants shared it was *"nerve wracking"*, whereas others described it as *"boring"*. Participants also shared finding parts of the assessment process challenging due to their autism. One difficulty was the *"time it took"*:

"It was long. It was a very long. It was a very, thing was about an hour, two hours, I think it was for the assessments, so it was a very long and draining. So, it took, I think we didn't get back until what was it, 7 o'clock at night, so it was like a whole day out and I don't like being out for like too long so travelling there and back and whatnot, it just kind of took it out of me so." (Participant 29)

Similarly, a parent reported the appointment itself disrupted their family member's schedule:

"probably the worst part of it was having to take him out of his daily activities to go to make an appointment". (Participant 21)

Another autistic participant reflected on the sensory experience:

"The assessment itself, some of the questions were OK, some of them were a bit too much. I didn't like the bright colours and the sporadicness in the many different colours at once." (Participant 1)

Some family members commented on the assessment being a *"tick box exercise"*, with one parent highlighting they didn't feel the person's learning disability was adequately considered:

"I think that erm a lot of the assessments are obviously scoring ticking boxes and I don't always think that if you've got a learning disability that they take, it doesn't some of the things don't apply because you've got a learning disability as well. They're kind of geared to the more able sort of person with autism…it doesn't take into consideration the learning disability as well, so I think when the assessment's done, I think it will be beneficial to have a separate section, for people with a learning disability because you get a very, the answers would be different. And should really be tailor made to that in a separate assessment." (Participant 20)

Despite some participants experiencing challenges during the assessment process, nearly every participant said they would recommend it to others *"so that they know"*, with comments such as *"definitely go for it"* and *"there's no harming going for assessment"*. No participants expressed thinking others should not be assessed, but more that it is personal choice. A couple of participants also stressed the importance of attending assessment in person as opposed to online, as "*some things could be missed via video"*.

Subtheme Three: Initial Reaction

There was some variation in participant's emotional responses when the autism diagnosis was given, however also widely shared experiences across both autistic participants and their family members. Most family members shared *"it wasn't a surprise"* and that *"the*

diagnosis just confirmed what we already knew". The most common reaction experienced by autistic participants was *"relief"*:

"It was a bit of a relief to be fair. It was like because obviously I'm like look up stuff. And I saw that stuff online and, you know, you know what you do. And then it was kind of like a relief off my shoulders because I, like, knew that I had it, if that makes sense. So being diagnosed with it was kind of a relief." (Participant 15)

Family members similarly expressed relief:

"This sort of relief, really just confirmation that that, yes, he's been finally got a diagnosis of long last, and we can move forward you know. And get the right help and support that he needs." (Participant 4)

Some autistic participants expressed that they also *"felt happy I got it",* which was shared by some parents as their beliefs were confirmed:

"It was like punching the air and going yes, I was right all along." (Participant 11)

For some autistic participants, the diagnosis initially bought up feelings of anxiety due to uncertainty they experienced, however this appeared to dissipate once they were provided with more information:

"Well, erm, well just a bit bit worried about erm, implications that might affect me".
(Participant 3)

"I felt panicky…What is it? What is it? Oh, what have I got now? (Laughs)."
(Participant 28)

The above participant's quote highlights a potential difference for the learning disability population, as they may have had more experience of healthcare appointments and assessments due to their learning disability. This is mirrored by a different participant reflecting it was just *"another diagnosis"*. For those that had not previously suspected autism, the diagnosis provoked different reactions. One parent shared:

"I just couldn't believe that she, they diagnosed her with autism. And it just shocked me."
(Participant 16)

And for an autistic person of another family, it triggered feelings of anger as they felt let down:

"when he had the booklet saying autism, it was like, urgh. I was just. I was just angry. I was angry because I thought [in] my childhood someone could have helped me. And it may be it would have been a lot more, easier." (Participant 24)

Lastly, for some participants the diagnosis carried little impact. One autistic participant shared that *"it didn't make any difference to me"*, and a family member echoed this when talking about her daughter being diagnosed:

"Well, in natural fact, she doesn't know anything. She just who she is. So, whether she's got autism or she's got, she doesn't know. She just there and she just carry on. So, it didn't, it didn't make any difference with her." (Participant 7)

This theme highlights the potential impact that having a learning disability can have; some participants suspected that this delayed autism being identified due to diagnostic overshadowing, yet some felt it facilitated support in the absence of autism diagnosis. Most participants found the assessment itself acceptable however it included challenges for some, and others felt the presence of a learning disability was not adequately accounted for. Many participants experienced relief on receipt of the diagnosis, however more difficult emotions arose for those that had not expected it, highlighting the impact that previous experiences, understanding, and the meaning that is made from later diagnosis can have.

Theme Two: Understanding

The theme Understanding relates to how the autism diagnosis has impacted participants understanding of themselves or their family member, subsequently influencing their wellbeing and behaviour. It also relates to participants understanding of autism itself, including greater understanding as well as uncertainty or confusion.

Subtheme One: Explains Behaviour

The most reported impact of receiving an autism diagnosis was that it gave participants a *"better understanding"* and *"things became clearer"* because the autism explained behaviour and gave it *"a reason"*. Autistic participants shared it gave an explanation to themselves and others:

"I now know that there's something that explains this behaviour that I'm, yeah, that the way I behave and the way I act that there is something that explains it all to people and to myself." (Participant 1)

And provided answers:

"Yeah, it was more so of an answer. What's going on and why I'm like this." (Participant 1)

This supported people's understanding of their behaviour:

"I understand a lot why I do certain things now. And it's just like, I don't know…it's like understandable why I do them sort of things now." (Participant 15)

This was echoed by family members as it *"makes you feel there's a reason for things",* as it gave *"the knowing that there is something going on in her head that might not be going on in*

everybody else's". Family members reflected that this increased understanding of their relative has influenced their interpretation of their behaviour:

"I'm glad she's got the diagnosis; it's made us more attuned to why she does what she does because she thinks differently. She's got autism. She can't help it. Right? So we in that respect, we we we're more understanding and we're more accepting. You know, we're more accepting of why she does what she does. So yeah, the diagnosis has helped and explains a lot why you know the behaviour and everything." (Participant 12)

Autistic participants also commented on feeling that their family members understood them and why they do things better. For example, one participant referred to her preference for a particular shop:

"[They are] probably understanding more better. They're still learning, but they got understood about the certain day shop now." (Participant 25)

Having an explanation and improved understanding of their relative's behaviour appeared to reassure family members as they were "*not as confused"* by their behaviour:

"it's giving me the settlement that this is what [relative] is…I've read about the autism and the rest, but then it gives you the settlement that with all that she's doing or before that she's going through is because of this. That's why she's doing that. So, then you have the better understanding that she does what she does." (Participant 7)

Understandably as well as providing some answers, for some it raised new questions as participants had varying levels of knowledge of autism prior to diagnosis:

"it answered some questions, but then I opened some more. But then my psychiatrist is helping me to answer them." (Participant 25)

Subtheme Two: Comprehension of Autism

Participants reported benefit from being provided with an explanation for some of their or their relatives behaviour, however there was variation in how much they already knew, researched, and learnt about autism following diagnosis, impacting their comprehension of the condition itself. One autistic participant demonstrated this sense of both knowing and unknowing when referring to one of their family members understanding:

"I think she sort of sees it as something that while she doesn't understand what autism is, she identifies that it's something that sets me apart from different people." (Participant 31)

Several participants shared they were given psychoeducational materials from services following diagnosis, and some autistic participants reflected on ways it applied to them such as *"autism makes me struggle with day-to-day activities"* and *"we have a one-track mind on a certain topic"*. Some of the family members shared their autistic relative *"doesn't know"* and "*no understanding of it"*. Similarly some autistic participants voiced struggling to understand what autism is, which for some brought difficult emotions:

"I still don't, not quite understanding this autism thing, you know, and it's like, and I'm trying to understand it, but the more I try, I get angry because I just don't get it. I just don't. Understand. And I have to ask my brother or my mum about this autism because I say I simply don't understand any of it." (Participant 24)

This highlights how having a learning disability as well as autism may influence the impact of autism diagnosis, as for some the consequences may be indirect, through family members and carers. However, this was not exclusive to participants with a learning disability, as some family members shared their unknowing:

"we don't know what to do with it, do we? Because we don't understand what it is ourselves." (Participant 26)

Similarly, another parent shared:

"It is just hard for me, totally hard because I don't understand, that brain pattern." (Participant 16)

Another commonality family members shared during interviews was how it was difficult to differentiate between different characteristics their relative has. Having co-occurring conditions could make it *"difficult to tell which bits making the behaviour be like it is"*. Also, whether certain behaviour could be attributed to autism or not, which could pose challenges as they are unsure how to respond:

"I just think sometimes…sometimes certain behaviours can be excused. It's hard to know is it the autism or is it a behaviour, a bad behaviour, and it's finding that balance to know where some people would say she's just misbehaving now. You need to try and get back or, is it, she's not misbehaving because it's due to the fact that she, of the autism. And I think that's a really tricky, it's very grey at that area." (Participant 20)

This theme suggests that receiving a diagnosis of autism can increase people's understanding of themselves or their relative; however, it can be difficult to identify whether characteristics and behaviours are driven by their autism. This uncertainty could make it difficult for family members to know how to respond to their relative. In addition, it suggests that some people could benefit from being supported to learn more about autism as a condition following diagnosis, if feelings of confusion are evoked.

Theme Three: Wellbeing

The theme Wellbeing relates to how the autism diagnosis has affected the autistic individual's health, including their view of themselves and how they and other people manage experiences to support their needs.

Subtheme One: Identity

During interviews autistic participants reflected on whether the diagnosis had impacted how they view themselves and shared varied responses. Some shared before the diagnosis they *"thought that I was just weird"* and *"felt that since I was a kid growing up and everything, I sort of sort of didn't fit in*." Receipt of the diagnosis gave them a stronger sense of self, as they learnt more about themselves:

"before I felt like I was missing still missing pieces of like myself as a whole. So, when I figured out that after my diagnosis I got autism, I started to put the pieces more in link and just figuring out who I was more." (Participant 5)

This served to normalise participants experiences as they learnt "*it's normal to be different"*, which reduced feelings of isolation:

"It feels like I'm not alone and I know erm, it's one of the, one of the things that some autism, some autistic people do." (Participant 10)

This appeared to act therapeutically for participants as they gained *"more like acceptance towards who I am as a whole"*. This was supported by some family members' observations:

"I just think that it's brought out a different kind of confidence in him…I don't think he's as hard on himself". (Participant 32)

Others shared the diagnosis had not affected their sense of identity as they are "*still just me"* and *"don't see myself as any different"*, therefore little changed:

"I'm still exactly the same person and everything so yeah, I don't think it's changed anything, to be honest." (Participant 13)

Subtheme Two: Given Permission

Participants also shared that being diagnosed with autism granted them permissions to show more of themselves and have needs, which supports their wellbeing. Several referred to having masked their autism *"to fit in best I could"*. Autistic masking, also known as camouflaging, involves adapting behaviour to align with allistic people and often entails the suppression of autistic traits (Scheeren et al., 2025). Participants shared that them and others knowing they are autistic, enabled them to *"unmask and do things":*

"from what I've understand from myself, so many autistic people are undiagnosed, mask themselves, and it and masking for so long hurts them. And now I'm diagnosed, I'm diagnosed, I can, I feel relieved that I can not have to mask. I can stim, I can do whatever I want. And not have to worry about being told off." (Participant 1)

The above participants quote highlights the consequences of having to mask, and suggests others respond differently to their behaviour due to knowing they are autistic. Another participant mirrored this increased comfort around others:

"I don't feel as anxious anymore, I feel that I can talk to someone if I've got any problems, and if I tell them that I've got autism then and then how to treat me, how to better treat me." (Participant 10)

As well as feeling a sense of permission from others, the diagnosis appears to have enabled some autistic participants to grant themselves permission to do things differently, as noticed by family members:

"*She has a badge now on the bus. She didn't like sitting close to people. Now she can gain space…[She] doesn't like busy or noisy places and will take herself away now". (Participant 9)*

"*And you go well. I can't help it, can I? Because she's got to do it in a certain order. But now you don't mind and you'll go, oh, well, you know, I've got to do it in a certain order." (Participant 11)*

This appears to have subsequently improved people's wellbeing, as one family member noted their relative "*feels happier"* as they are *"allowed to be different"*, and another shared their relatives' emotions and frustrations can be channelled in a different way now. Despite many participants feeling that the diagnosis has given them a sense of permission, one participant did express they still mask as they've *"been doing it for such a long time. It's it's just kind of normal."*, which highlights how ingrained masking can be due to having to abide by social pressures.

Subtheme Three: Learnt Strategies

Many participants shared that following diagnosis, through services and their own research, they have learnt strategies that help them or their relative to support their wellbeing, as explained by a parent:

"I think we've learned a lot of, what's helped him is we've learned a lot of strategies coming here on the how to manage certain things and ways that he can manage them himself as well that obviously I wouldn't have known about." (Participant 20)

These included strategies such as using *"visuals"*, *"list writing"*, and setting *"routines"*. For some participants these were new strategies, whereas for others they already utilised these but *"the diagnosis has encouraged it"*. Another parent shared they give their child more notice of what's going to happen now, which better prepares them:

"*seeing new people is also another issue with her, so it's like you have to preload her that you are going to see this person and and then she's aware of that and that settles her other than that's it her mood also changed. So that's the way we are doing it now". (Participant 7)*

Several autistic participants also reflected on strategies they've learnt that they use to regulate themselves:

"I have been getting like a lot more stuff to accommodate myself with like a weighted blanket, some fidget toys and a bit more stuff that can help me out." (Participant 5)

In addition, one autistic participant shared that the diagnosis has made them consider the medication they take as it *"helped me question whether I need it or not"*. This was because difficulties they had experienced had been considered as due to a psychiatric

condition that they were given medication for, therefore the autism diagnosis challenged if this was required. This highlights the impact that autism diagnosis could have on people's medical treatment, as it can change the way their needs are understood.

As well as practical strategies, several family members shared that through their relative being diagnosed, they learnt of clubs for autistic people which has enabled them to connect with others:

"*the club that he goes to he's, which is fantastic, there such a good club, he, he can relate more to the others and he's able to make more friendships" (Participant 20)*

"Yeah, I think what it is as well, because he likes to just talk to someone that has exactly the same interest as him and where he quite repetitive, he's gelled with people that are similar and it has the same interests where other people wouldn't really want to sit and talk about just that only, certain topics or, so he has gelled with certain people that are autistic." (Participant 20)

This theme suggests that for some, receiving an autism diagnosis can create shifts in how they see and therefore feel about themselves, whereas others view themselves the same way. It also highlights the therapeutic potential of autism diagnosis, as for many participants it enabled greater self-esteem and confidence, as well as the learning of ways to support their wellbeing that they may not have learnt otherwise.

Theme Four: Support System

The theme Support System refers to how the autism diagnosis has influenced the wider system around the autistic individual, impacting their and their family members experiences. This includes support from services, how they are treated by other people including their family, and ways it has impacted their family members personally.

Subtheme One: Professional Input

Some participants reported that following diagnosis the service that completed the assessment provided them with some post-diagnostic support, with family members noting they were given *"guidance from professionals on how to deal with things"* and were signposted to *"organisations that can help"*. Participants also referred to being given written information about autism for their own learning. Some participants also referenced input from social care; for some, *"social care support has come in place since autism diagnosis"*, whereas other participants already accessed social care. One parent shared *"we've been offered more respite hours"*, and family members had an understanding that *"you have to have a diagnosis to get the funding"*. One of the autistic participants shared the diagnosis affected the benefits they receive:

"I've been given disability allowance and all PIP you know, that helps as well". (Participant 17)

Despite these reports, the general consensus was that *"nothing really has changed"* in terms of professional input, as *"support that we have is the same before the diagnosis"*. Some participants expressed that they thought the diagnosis would facilitate greater change:

"Well initially I thought, yes, you know we can help her now, but it's just it's not turned out that way." (Participant 12)

Some family members shared feelings of frustration regarding this, as they questioned "*is that it?".* This was echoed by some autistic individuals, as demonstrated by one participant:

"I just kind of feel like they've diagnosed me and there's nothing else really". (Participant 15)

Some reflected that although they feel little has changed so far, they think the diagnosis could enable options in the future:

"At the moment there's no change in anything whatsoever, you might find stuff comes available. It opens, it could open different doors, maybe that we're not aware of, if that makes sense." (Participant 21)

One family member also highlighted it can be difficult to know how the autism diagnosis has impacted the support they receive, as they were accessing services due to their learning disability:

"services as in government services, because I don't know if he would have got what he's got now, I don't know". (Participant 14)

Subtheme Two: Treatment from others

As well as input from services, participants reflected on how the autism diagnosis has impacted the support they receive from family or provide as family. Family members shared feeling they have greater acceptance and are *"more understanding"* of their autistic relative now:

"I'm definitely more patient with her now. I don't fly off the handle as much with her now." (Participant 12)

This appears to be because the autism diagnosis has provided an explanation for behaviours that they can feel challenged by, because their relative *"can't help it"*:

"She has odd behaviours, they were infuriating…now we know why. I am more tolerant now." (Participant 9)

Some autistic participants agreed with this, advising they get *"a bit more support now"* from family, or are supported differently:

"She lets me have like time to try and cool down. Instead of going straight for me to see if I'm alright." (Participant 25)

For other participants, the support they receive from family hasn't changed following their diagnosis, as people *"just see me as normal [name]"*:

"I think nothing has really changed. Because with the support system I have with family, friends and just general mutual contacts they've treated me the same way as they did before my diagnosis." (Participant 5)

Several participants also commented on how people outside their family may treat them differently in light of the autism diagnosis. One autistic participant shared you can tell people you're autistic, so that they are less judgemental:

"Because once you know what's wrong with you, and if anyone starts judging you, you can literally say, well, I've been tested for this, and it turns out, I got this. And then some people might, you know, back away and like, sorry we judged." (Participant 25)

Whereas others felt the autism diagnosis itself could create judgement as *"there's still stigma with it"*:

"We're in a world where we just stereotype. We stereotype everyone. And because you look like this, because you got this diagnosis, this must be how you behave. No." (Participant 2)

Due to this, some participants chose not to share their diagnosis with others.

Subtheme Three: Parenting

Another way the diagnosis had an impact on family members, was that it led some of the parents to reflect on their general parenting. As the autism diagnosis was given in adulthood, it made some question how they had parented, as they thought they had done everything they needed to do for their child:

"it's not that I was a bad mum or nothing like that, you know. But I just thought I, I've done everything and then for this, perhaps that's what I was shocked, you know? Because I thought I'll done everything". (Participant 16)

Some parents appeared to blame themselves initially following the diagnosis, for the presence of autism and/or when it was recognised:

"she felt erm that it was her fault that she hadn't recognised it. But and I think she blamed herself for, maybe not so much now, but for that brief time on finding out…she said she felt that she should have pushed a bit more". (Participant 32)

"[I] did wonder if it was my fault what he's got autism. It wasn't, but I felt as though it was, and I felt as though maybe I could have done more if I'd known". (Participant 18)

For some it evoked feelings of guilt and regret regarding how they had treated their child:

"I feel guilty that I used to be less tolerant". (Participant 9)

"I remember doing that. And now regretting that, I'm thinking I should, that wasn't very fair on him." (Participant 14)

Others shared that they had questioned their parenting ability, experiencing thoughts such as *"what have I done to create that?"*, in regard to their child's behaviour, and that the autism diagnosis reduced feelings of self-blame:

"That no matter how hard I tried, certain things just weren't, weren't going to fall in place because of the autism…So yeah, it weren't me going wrong. As much as it felt like it, sometimes it wasn't. It was, I was battling against the autism as well." (Participant 2)

A couple of parents reflected on how other people had perceived the way they parent prior to the diagnosis. One participant shared *"[His] dad said I was a bad parent"*, due to their child's behaviour. And another shared how the diagnosis made others view their parenting differently:

"other people think I'm pandering to her. And now they will go, Oh, now I understand why you're doing that. you see, instead of, I used to just say to, other people would say, oh, you know, you're being too soft…So therefore I'm perceived a soft a push over, not doing her any favours for the outside world. But I see it that I'm keeping her calm". (Participant 11)

This theme reflects that participants felt the autism diagnosis had little impact on input from professional services, highlighting the importance of discussing potential consequences and expectations following diagnosis prior to assessment. It does however show that the diagnosis enabled some family members to have more patience with their autistic relative, whereas for others social support remained the same. It also highlights one of the ways that receiving an autism diagnosis in adulthood can impact family members in a caring giving role, which may subsequently influence the ongoing support that they provide.

Theme Five: Language

The theme Language refers to ways that autism as a diagnostic label and word has impacted participants, through their own and others use of it, including some reflections on how participants feel about it.

Subtheme One: Labelling

Many participants shared that the autism diagnosis has *"put down into words"* the autistic person's experiences and difficulties and provided *"a name"*. Some family members reflected *"so that other people would listen, I needed a diagnosis"* and felt this was a necessity:

"you have to have a diagnosis to get the funding for them all that sort of that malarkey". (Participant 21)

Some families felt the addition of the autism diagnosis alongside *"learning disability"* was helpful as it provided more information:

"Well, we've never had a name of anything before. We've just had learning disability. Which doesn't really tell you an awful lot about the problems that she's facing. It just says that there's a problem." (Participant 22)

And voiced that diagnostic labels are needed in order to access specialist help and information for their own learning:

"You can perhaps channel help from people in that area, you know, get their expertise. Which if you, you haven't got the label, you can't really source it." (Participant 23)

Others felt the diagnostic label made little difference:

"we'll be handle her the way she she is. And that's how we are carrying on because but it just that we've got a name to whatever is happening with her." (Participant 7)

And one family member expressed concern that the autism diagnosis would result in less support, due to it being a lifelong condition as opposed to a short-term difficulty:

"I am a bit worried about what that's going to mean for him moving forward, whether they'll just sort of like...It sounds horrible, but I feel like once you've got an autism diagnosis it's like you're pushed aside a little bit. It's not as much up there on your mental health…so I'm hoping that it doesn't have a negative impact on the support that he gets." (Participant 32)

There were also some variations in opinions on the idea of labelling. Some autistic participants appeared to like having a diagnostic label, as one parent said to their relative *"you like to have a label, don't you?"*, and another shared:

"I think she likes the label, wears it like a badge of honour." (Participant 9)

Whereas a couple of family members shared comments such as *"I'm not into labels"* as *"everyone's different"* and labels can be reductionistic and/or enable assumptions:

"But is that every autistic person, or is that you? And that's the line, because at the end of the day with the diagnosis, every individual person is different like, we're so quick to diagnose and label someone, and that's how stereotypically that person should behave. But is it? Is that the autism? Or is it that person?". (Participant 2)

Subtheme Two: Communication

Some family members shared that the autism diagnosis acts as a *"way to communicate"* with others when required regarding their autistic relative. They advised their relatives needs can be *"quite hard to describe"* to others and using the label autism *"makes it easier"*. Family members reported that the autism diagnosis was readily recognised by others:

"But it's much easier to say like, if you're going somewhere or doing something, he has autism, it's just so much, yeah, it's it's just more on, everyone understands". (Participant 14)

And that people had been receptive of this:

"it's almost like it's a a light bulb or something that goes on like you say, oh, my son's got autism. And they're like, ping, OK, we must pay attention now." (Participant 2)

Family members reflected it's a quick way to explain their relative's behaviour to others to correct or prevent misinterpretation:

"The diagnosis acts as a short hand to communicate with others what [she] needs. She needs to leave busy noisy places, we used to say don't as its rude or others would think it's rude, but now we know and can explain to others." (Participant 9)

And that sharing the diagnosis has helped them get access support:

"The more we've got labelled, the easier for for her. Because it's a case of, as they said to you didn't the doctor whatever her name was, she said you could have a little card that if you felt embarrassed to say anything, you could just push your card that says I have autism, please would you assist" (Participant 11)

Or been shared by family members so others make amendments:

"I have used it a few times, but when I was in hospital because I was ill and that she's in the waiting room and they kept waiting. I go you can't keep me waiting here and they're going, you just have to wait, I goes, my daughters sitting out there she's got autism. Oh, I have used it as an excuse." (Participant 16)

This theme highlights some of the potential benefits and pitfalls of diagnostic labelling, and that people can relate to this in different ways. It also highlights the utility of diagnostic language in supporting quick communication with others, when understanding is mutual.

Conclusion

The RTA revealed five themes consisting of 13 subthemes, exploring the impact that receiving a diagnosis of autism can have for adults with a learning disability and their family members. This includes how it affects autistic people and family members individually and collectively, including interactions with each other and wider systems. It also includes participants experiences across different timescales including prior to and during assessment, and post-diagnosis. One of the most influential aspects appears to be how the autism diagnosis has altered participants understanding of themselves or their relative, leading to subsequential changes to their wellbeing and the support they receive or offer. Findings are discussed in the following chapter including how they relate to and extend current literature. The potential implications of the findings as well as important considerations regarding the project as a whole are also discussed.

Chapter Five: Discussion

Chapter Overview

This chapter presents a discussion of the study findings including how these relate to and extend current literature. Following this the strengths and limitations of the study are considered. The implications of the research are then discussed, as well as how the findings will be disseminated. Lastly, a section on the researchers' reflections is presented, followed by a conclusion of the study.

Summary of Findings

This study aimed to explore the impact of autism diagnosis for adults with a learning disability and their family members, to begin filling the gap in literature regarding this population, with the hope that the support provided is tailored to meet their needs. From the 18 interviews that were completed, five main themes were constructed: Journey to Diagnosis, Understanding, Wellbeing, Support System, and Language.

Theme One: Journey to Diagnosis

The theme Journey to Diagnosis and its relevant subthemes encapsulates participants experiences of autism being suspected, their experiences of being assessed, and their initial responses to the outcome. The majority of participants felt it would have been better if the autism diagnosis had been given earlier, due to thinking this would have helped improve their understanding of themselves or their relative and facilitated more help and support from services. Earlier diagnosis can enable the implementation of evidence-based intervention which can support autistic children's developmental outcomes, enhancing autistic children and their family's quality of life (Augusto et al., 2025). However, several participants who

were family members felt it did not matter that autism was only diagnosed in adulthood, as their relative was accessing specialist education due to their learning disability. In general students with a learning disability are more likely to attend special educational needs schooling, and therefore they may have access to more support than those in mainstream schools (Snozzi et al., 2025). This does however rely on the learning disability being diagnosed, which the synthesis in Chapter Two showed can be a long and challenging process. These participants reflections lean into the potential benefits of having a co-occurring learning disability as specialist support may be being offered, however research has evidenced that learning disability is highly associated with under and misdiagnosis of autism (Hurley & Levitas, 2007). Lau et al. (2022) researched the timing of autism diagnosis in people with additional developmental conditions and found a prior diagnosis of learning disability significantly delayed autism diagnosis. Contrary to this, Loubersac et al. (2023) found co-occurring learning disability related to earlier diagnosis of autism, however this was also linked to evident language delay. Some participants shared a belief that autism had not been suspected sooner due to diagnostic overshadowing, in which behaviour is attributed to the learning disability, which caused frustration. Diagnostic overshadowing is commonly experienced by the learning disability population and contributes to health inequalities (Javaid et al., 2019). Haller et al. (2022) compared levels of unmet healthcare needs in children with a learning disability, autistic children, and autistic children with a learning disability. They found that children with a learning disability alone were the most likely not to receive required medical care, followed by autistic children, and then children with both. This research suggests if both conditions are known, children are more likely to receive healthcare when needed which calls for early identification. Research has also highlighted that autistic people without a learning disability are at greater risk of misdiagnosis than the allistic population, particularly of psychiatric conditions (Kentrou et al., 2024; Fusar-Poli et

al., 2022). Many of the autistic participants in this study shared they had received diagnoses of mental health conditions long before their autism diagnosis. This reflects the often-arduous journey neurodivergent people can experience in obtaining accurate diagnosis, which can be accentuated by having a learning disability. Increased education and training regarding psychiatric conditions in the learning disability population is needed to reduce biases in diagnostic processes (Dell'Armo & Tassé, 2025). In addition, considering the results of the synthesis in Chapter Two, parents of people with a learning disability may have experienced a long journey when accessing a learning disability diagnosis. Research highlighting the benefits of diagnosis supports the use of medical categorisations of neurodivergence, however this sits within the context of public health services operating from the medical model.

Participants shared that clinicians, family, and friends suggested they could have autism due to their behaviour, and all agreed to attend for assessment. The vast majority also stated they would recommend autism assessment to others if they suspected they were autistic, reflecting their perceived value of "finding out". Several participants expressed it is an individual choice. There was some variation in how participants experienced the assessment process. A few family members voiced it had taken a long time for their relative to be assessed, however for others it was a quick and easy process. Several autistic participants shared that they felt nervous at the start of their appointment, however the assessing clinicians were friendly and put them at ease. This may be further helped by clinicians orientating people to what the assessment will involve prior to the appointment. The majority found the assessment acceptable and a few commented that they or their relative found it boring. Some participants reflected on more stressful aspects such as having to break routine to attend, the pressure of completing tasks under time limits, observing bright colours, and the tiredness they felt afterwards. Clinicians could support people to consider what might

be helpful in preparing for and attending the assessment in advance. An important reflection shared by a family member was that the assessment did not appear to adequately consider the presence of a learning disability. They suggested that a separate section is devised to account for this. Assessment tools such as the ADOS and ADI-R are intended for people without a learning disability, however, are used in learning disability services as per NICE guidance (NICE, 2017, 2021) as specific assessments for this population do not exist. This is an issue across different types of neurological testing; tests such as the Wechsler's Adult Intelligence Scale use nation-level population-based normative data (Wicherts, 2016). Using traditional methods to measure IQ in people with a learning disability can lead to inaccuracies and clinicians should interpret the results with caution (Sansone et al., 2014; MacLean et al., 2011). This highlights another difference for people with a learning disability in the autistic population and supports the need for more research and the development of autism assessment tools specifically for the learning disability population to ensure accuracy.

The majority of participants reported feeling a sense of relief when the autism diagnosis was given, as it confirmed their belief and they thought it would lead to appropriate support. This mirrors Kiehl et al.'s (2024) research in which autistic people without a learning disability expressed finding out that they were autistic provided relief and clarity. This included the relief of parents, which contrasts with the results of the synthesis in Chapter Two where parents reported grief responses following their child's learning disability diagnosis. Similarly, Ooi et al.'s (2016) found parents experienced feelings of shock, despair, and anger when their child was diagnosed with autism. It is likely that these differences relate to the parents in this study having already been through the process of their child being diagnosed with a learning disability in the past; they may have already processed that their child has a neurodevelopmental condition and possibly experienced the benefit of diagnosis. Similarly, a few autistic participants shared it made little difference to them, as it did not change who they

were. This suggests the presence of a co-occurring condition and the life stage people are in may impact how diagnosis is received. However, a couple of participants reported more difficult emotional responses: shock and anger. In these cases, the autism diagnosis had not been suspected and came as a surprise. Both participants shared their interpretations linked to these emotions; one parent thought they must have missed something, and one autistic person thought others had let them down. This highlights the impact of the meaning that is made from later diagnosis, and the need for post-diagnostic support for people that would benefit from this. This study has provided new knowledge that many autistic people with a learning disability want to know whether or not they are autistic and would prefer that this was identified in childhood. In addition, it reveals the need for autism assessment tools specifically for the learning disability population.

Theme Two: Understanding

Theme two relates to how the autism diagnosis has affected participants understanding of themselves or their relative and linked to that, their understanding of autism. Autistic participants reported that the autism diagnosis increased their understanding of themselves as it provided an explanation for their experiences and behaviour, appearing to answer questions they had held about this. This aligns with Gellini and Marczak's (2024) findings that autistic people without a learning disability felt their diagnosis helped them understand themselves more. Participants also shared feeling it had enabled others to be more understanding of them, which family members reinforced. They expressed feeling the diagnosis gave a reason for their relative's behaviour, acted as a justification which appeared to increase their acceptance of their relatives' differences, and provided them with reassurance. Interestingly, the presence of a diagnostic label appeared to facilitate this without the need for comprehensive understanding of autism as a condition. Many family members voiced feeling they did not understand autism very well, which could at times make it hard

for them to know what to do following diagnosis. This came into play more so when they were unsure if their relative was intentionally behaving inappropriately or not, as it was hard to know how best to respond. This highlights the potential need for greater post-diagnostic intervention for parents, but also general education for the wider public to increase their understanding of autism. Many misconceptions about autism exist, and greater knowledge regarding autism can positively influence attitudes (Alsehemi et al., 2017; Kuzminski et al., 2019). Comprehension of autism was more varied in autistic participants. Several autistic participants referenced how autism affects them, evidencing the value of including autistic people with a learning disability in autism training delivered to clinical and educational settings. Some participants that were family members shared that their autistic relative was unaware of autism and that they were autistic, which highlights another potential impact of having a co-occurring learning disability. In these cases, the family members benefitted from knowing in order to support their relative. One autistic participant expressed difficultly in understanding their diagnosis, evidencing the need for post-diagnostic support suitable for people with a learning disability. These findings extend previous research by showing autism diagnosis also increases people's understanding of themselves for people with a learning disability, and/or their relatives understanding of them. Diagnosis appears to facilitate this even if people do not have a comprehensive understanding of autism.

Theme Three: Wellbeing

The theme Wellbeing reflects how the autism diagnosis has impacted participants sense of identity, ability to be themselves, and knowledge of strategies that can help them. There appeared to be two avenues' participants experienced regarding their identity following diagnosis. Many expressed prior to their diagnosis they felt different from others; this mirrors what parents reported in the synthesis due to their child having a learning disability. This may be linked to their learning disability; Kenyon et al. (2013) found participants with a learning

disability described themselves as different from ‘the norm’. This may be influenced by the stigma the learning disability population face which can negatively impact how they view themselves (Jahoda & Markova, 2004). Finlay and Lyons (2000) however argue that people with a learning disability view themselves as ordinary because disability is not central to their identity. Nevertheless, participants reported being diagnosed with autism increased their sense of identity which had therapeutic effects. Similarly to Gellini and Marczak’s (2024) findings, this facilitated greater self-acceptance which both autistic participants and family members had observed. It appeared to normalise participants experiences and reduce feelings of isolation as they became part of the autistic community; social groups can facilitate a sense of meaning and belonging (Koni et al., 2019). This supports the ethos of the neurodiversity movement as difference is normalised and celebrated. Research supports that identity is associated with wellbeing (De Lise et al., 2024), however self-esteem can affect this. Corden et al. (2021) found people with lower self-esteem experienced dissatisfaction with their autistic identity, whereas people with high self-esteem embraced this more positively. The other avenue participants reflected was that they did not view themselves any differently following diagnosis, as they are still the same person. This may support Finlay and Lyons’s (2000) argument that disability is not central to identity.

For many autistic participants, diagnosis appeared to increase their confidence and give them a sense of permission to act more authentically. This aligns with Jutel’s (2009) argument that diagnosis grants people permission to be different. A couple of participants mentioned masking, with one stating they felt able to unmask following diagnosis and another advising masking has become normal to them. As well as autistic people, people with a learning disability often practice masking during social encounters (Rapley et al., 1998). Masking can be very detrimental to people’s emotional wellbeing (Bradley et al., 2021); this may be exacerbated for autistic people with a learning disability as they may feel pressure to

hide more parts of themselves. Participants shared they allow themselves to do things differently more following their diagnosis, such as stimming to self-regulate or practicing things in a particular order. This suggests an increase in self-compassion, which Wilson et al. (2023) found autistic adults without a learning disability experienced following diagnosis. In addition, the diagnosis enabled participants to learn of new ways to support their wellbeing such as implementing strategies that can increase predictability and reduce anxiety. This included regulation methods such as focus tools and weighted blankets. It also appeared to open up new opportunities such as social groups set up for autistic people which the participants that attended found very beneficial. These findings provide new insights that autism diagnosis can affect people with a learning disability's sense of identity, which appears to enable greater self-confidence. It also allows people with a learning disability to become part of another community and learn strategies that improve wellbeing.

Theme Four: Support System

The theme Support System encapsulates how the autism diagnosis has affected the support that participants receive including how family members have been impacted. In terms of input from NHS services, the assessing service gave participants information on autism and provided signposting to relevant organisations following diagnosis. This mirrors the post-diagnostic support specialist autism assessment services in the UK offer (Norris et al., 2025). The general consensus from participants was that outside of this, support from healthcare services remained the same. Some family members expressed that they expected more post-diagnostic support and a few were dissatisfied with the amount they received. When offering recommendations to services, most participants suggested that they offer more support. This mirrors the findings of Crowson et al.'s (2024) research, in which autistic adults wanted more post-diagnostic support as they felt the amount they received was inadequate. At the time of interviews most participants were still under the care of the assessing service. This reflects a

difference for autistic people with a learning disability as in specialist autism assessment services, people are discharged following assessment. In practice there are large discrepancies between good practice guidelines and what services offer (Scattoni et al., 2021). In addition, the discourse and therefore expectation regarding medical care is that diagnosis is followed by treatment. This is where neurodevelopmental conditions differ; they are not diseases to be treated, however existing in diagnostic manuals may encourage people to think otherwise, therefore expect to be offered treatment. Several participants shared that the diagnosis affected their involvement with social care; this is interesting as social care is designed to be needs led as opposed to diagnosis led. In addition, some participants were unsure what was being offered in relation to their relatives' learning disability or autism; this highlights another difference for autistic people with a learning disability as they are more likely to already be accessing support due to their learning disability.

Participants also reflected on how the autism diagnosis had impacted interactions between them, which appeared to fall in two directions. Most family members reported that they, along with other family members, had become more patient and tolerant of their autistic relative. Autistic relatives that were present echoed this, sharing their families had become more understanding. There was a sense that the diagnosis alleviated blame and fault, suggesting family members gained greater empathy. This aligns with Milton's (2013) double empathy theory which argues that frictions exist due to allistic people lacking empathy for, and positioning autistic people as, problematic. Other participants shared that the diagnosis had made little impact and that they treated, or were treated, in exactly the same way as prior to diagnosis. In terms of people outside of friends and family, several participants expressed they or their family member chose not to share the autism diagnosis due to anticipation of judgement and discrimination. The learning disability population already has to manage stigma which negatively impacts wellbeing (Kenyon et al., 2013). The results of the synthesis

in Chapter Two showed that parents and their children experienced discrimination due to learning disability; this may have encouraged parents not to tell people about their relative's autism diagnosis and/or advise their relative not to tell people about it with the intention of protecting them. Participants fear of stigmatisation evidences the principles of the social model of disability and its call for attitudinal change.

Some participants that were parents also reported that the autism diagnosis had made them reflect on their parenting. A couple of parents voiced initially feeling that their child's autism was their fault before learning that this was not the case. This was similarly a finding of the synthesis in Chapter Two as parents reported feeling responsible for their child's learning disability. A couple of other parents shared feeling regret and guilt for having been less accommodating of their relative, potentially experiencing hindsight bias. As Legg and Tickle (2019) found parents of autistic children experienced guilt, they argued the importance of post-diagnostic support tailored to parents. Related to this, parents' perceptions of their parenting ability has been associated with parental success and child outcomes (Jones & Prinz, 2005). For other parents the autism diagnosis facilitated the opposite response, a relinquishment of responsibility as they attributed their children's behaviour to being autistic instead of a reflection of their parenting. It also helped one parent to feel more confident in how they support their child, in the face of other people's opposing opinions. These findings offer new knowledge that autism diagnosis can affect the way family members support people with a learning disability. It also builds on research exploring how parents are impacted; diagnosis may bring feelings of guilt or offer reassurance for parents of people with a learning disability regarding their parenting.

Theme Five: Language

The final theme relates to language, the diagnostic label 'autism' and how participants have utilised this. Several family members stressed the importance of gaining a diagnostic label as it provided more information regarding their relatives' needs and was viewed as a necessity in order to access support from services. They also touched on needing a diagnosis to know what to research or who to contact for help. This is reflective of how services operate from the medical model; medical diagnosis is required to obtain access to support; however, this perpetuates the view of neurodevelopmental conditions as deficit based and that neurodivergent people deviate from normality. Family members did however report that their autistic relative liked having a label; diagnostic labels can help people frame their difficulties less personally and offer people clarity (Rose, 2013; Jutel, 2009). It is possible people with a learning disability may find labels particularly helpful as they may provide scaffolding to support their understanding and provide a sense of certainty. In addition, as the prevalence of autism is increasing, more people are referring to being or suspecting that they are autistic, and as mentioned prior, being part of a community provides a sense of belonging (Koni et al., 2019). This may be particularly valuable for people with a learning disability due to the social marginalisation that they face (Jansen-van Vuuren & Aldersey, 2020). A couple of family members expressed feeling the label autism made little difference, as they continue to support their relative in the same way, and labels can be reductionistic. One parent expressed that labels equate to stereotypes which fail to acknowledge people's differences. However, many family members voiced the utility of their relative's diagnosis in assisting their communication with others when needed. Diagnoses can offer explanations (Jutel, 2009) and participants found that telling others their relative was autistic acted a quick way to express their needs and/or access required accommodations. The utility of diagnosis as a form of communication does however depend on other people's understanding and perceptions of

these. This supports the need for greater public awareness of autism, as argued by Alsehemi et al. (2017). These findings provide new insights that people with a learning disability may appreciate labels due to what they can offer, and that they and their family members can use them as a shorthand to communicate.

The results of the RTA reveal that autism diagnosis can impact people with a learning disability and their family members in different ways and to varying degrees. For the majority of autistic people in this study, this included gaining improved understanding of themselves, increased self-acceptance, and greater knowledge of ways to support their wellbeing and confidence to do so. For the majority of family members, this meant greater understanding of their relative, increased tolerance when supporting them, and a method to communicate their needs to others. The findings offer new knowledge and highlight the differences that autistic people with a learning disability experience to those without; this included the timing of autism being identified, the support they receive, and the applicability of assessment tools. This supports the need for more autism research on people with a learning disability, and the development of specific assessment tools for this population. Further implications are discussed later in this chapter.

Critique of the Study

There are both strengths and limitations of this research that require consideration. Firstly, the study itself is novel, attempting to address the significant gap in autism research by including people with a learning disability. As reported in the introduction, autistic people with a learning disability are significantly underrepresented in autism research despite high rates of co-occurrence (Russell et al., 2019). People with a learning disability are excluded globally in health research, despite wanting to be included (Bishop et al., 2024). This may be

due to researchers and ethics committee concerns regarding ability to consent, lack of confidence working with this population, and limited time to ensure the research is accessible (Bishop et al., 2024; Reuben et al., 2025). In Russell et al.'s (2019) meta-analysis of autism studies, an estimate of 94% of participants across all studies did not have a learning disability, despite findings that 33% of the autistic population have a co-occurring learning disability (Ziedan et al., 2022). As people with a learning disability have different needs from people without a learning disability (Matson & Shoemaker, 2009), the existing literature regarding experiencing autism diagnosis may not be transferrable. The inclusion of people with a learning disability is required to ensure this population can be supported effectively, and the ongoing increase in the prevalence of autism diagnosis exacerbates the relevance of and need for this research. It is also important to consider how families are affected, as people with a learning disability are often supported by family members well into adulthood. Research has evidenced that autism diagnosis can elicit a range of different emotions in the parents of those diagnosed (Ooi et al., 2016; Legg and Tickle, 2019), therefore the family approach this study adopted is valuable.

There is no definitive sample size qualitative research studies must adopt to determine adequacy, however in Hennick and Kaiser's (2022) systematic review, they deemed a sample size between 9-17 sufficient in order to achieve saturation. This is important as it indicates sufficient data collection as nothing new is being learned (Dahal, 2025). In this study 18 interviews were completed in total, and saturation was achieved as no new information was produced in latter interviews. The sample comprised of 32 participants and was varied, including a mix of autistic people and their family members, autistic people alone, and family members alone, which aligns with maximum variation sampling. This is a sampling strategy used in qualitative research in which different types of participants are recruited in order to

capture a wider range of perspectives; this can support a richer understanding of the research topic (Suri, 2011).

A limitation of the sample is that based on the researcher's clinical judgement, all participants that took part presented with a mild to moderate learning disability. This may restrict the applicability of the findings as people with a severe or profound learning disability may experience autism diagnosis very differently. People with different types of learning disability are often grouped together, which is problematic as it fails to acknowledge differences between populations (Forster et al., 2011). Research has evidenced important differences, for example Forster et al. (2011) found significant differences in behavioural and emotional difficulties in people with a severe learning disability compared to people with a profound learning disability. Holder and Gitlesen (2004) found people with a moderate learning disability reported experiencing greater mental health difficulties than people with a severe or a profound learning disability. Psychological wellbeing can influence how people interpret autism diagnosis (Corden et al., 2021), suggesting there could be significant differences for people with different degrees of learning disability. Research has also found that greater complexity of health status correlates with parent's levels of stress and quality of life (Barratt et al., 2025), suggesting family members may also experience autism diagnosis differently depending on the degree of their relative's learning disability and any co-existing health issues. In addition, although most autistic participants had been diagnosed in the last six months, there was variation in length of time since diagnosis across the sample. This may have prevented nuances regarding time from being adequately considered. It is also possible that people who perceived autism diagnosis more favourably were more likely to participate in this research. Those who viewed it negatively may have been less inclined to take part or may have declined an autism assessment altogether, potentially resulting in a biased sample.

There was some variation in participant demographic, however the majority of participants were White British and cisgendered. All participants in this study resided in the East of England, and all were assessed for autism through the same NHS trust which may have influenced their experiences. The significant majority were from a western, educated, industralised, rich, democratic (WEIRD) population. As WEIRD countries only make up approximately 12% of the world's population, the sample represents a small minority (Henrich et al., 2012). This is a critical issue in psychological research; for example, the majority of articles published in APA journals use American participants who make up less than 5% of the world's population (Arnett, 2016). Although qualitative research does not aim to generalise, differences across nationalities must be highlighted when considering implications. Differences in non-WEIRD countries may also heavily influence how autism diagnosis is received. For example, due to differences in service provision, in non-western contexts such as Africa and India, parents tend to provide more direct care for people with a learning disability (Raghavan & Jones, 2023). This may influence how much autistic people and their family members are impacted by autism diagnosis.

The National Institute for Health and Care Research (NIHR; 2022) recommend patient and public involvement (PPI) within research as this can improve its quality and relevance. This includes ensuring active collaboration with experts by experience across all aspects of the research process. This can be tokenistic which undermines the true value of PPI within research, however if done well, can reassure researchers regarding the quality of their work and enable advisors to feel a sense of contribution (Laidlaw et al., 2022). Within this study, experts by experience were consulted via a service development group set up by the recruiting NHS trust consisting of autistic people, people with a learning disability, and clinicians such as speech and language therapists. These experts by experience contributed to the development of the interview guide for participants with a learning disability to support

its accessibility. All advice was implemented and the researcher returned to the group to present the final version in case further refinements were advised. The researcher also contacted a charity that supports relatives of autistic people in an attempt to consult with family members regarding the development of the interview guide for family members, however, unfortunately was not responded to. Should the researcher have had more time, other organisations could have been contacted to achieve this. To further enhance the accessibility of the study, the researcher could have produced audio or video recordings alongside or in place of written documents such as the participant information sheet, as practiced by Hosking (2024) to address ableism in research.

Commonly reported limitations of qualitative research include that it lacks reproducibility, lacks generalisability, and is subjective therefore open to researcher bias (Mays & Pope, 1995). Contrary to this, it allows for in-depth exploration of people's experiences which enables rich understanding of phenomena (McGrath et al., 2019). This study utilised a qualitative methodology to align with its aim to explore how autism diagnosis impacts people with a learning disability and their families. Semi-structured interviewing was used as this allows researchers to respond flexibility to participants in order to further exploration and understanding whilst remaining focused on a particular topic (Adeoye-Olatunde et al., 2021). The ability to be flexible was deemed particularly important within this study; participants experience differences in social communication therefore in order to build and maintain rapport and ensure comfort, the researcher wanted to be responsive to interviewees which sometimes meant conversation diverged from the topic at hand. As appropriate the researcher guided the conversation back to questions on the interview guide. Although interviews operate in the context of research, attending to the relational aspect is essential to obtain quality data (DeJonckheere & Vaughn, 2019). To account for researcher bias, researchers can make notes documenting their interpretations and emotional responses

during interviewing to improve self-reflexivity (Clearly et al., 2014). As mentioned in Chapter Three, the researcher kept an audit trail of research activity and a reflective log noting thought processes regarding their influence on the project as a whole, but also during data analysis. The results of the RTA were also assessed by the research supervisors to consider this and ensure adequate themes and subthemes.

A possible consideration is that when participants interview together, the presence of each other could influence their answers. To account for this, the participant with the learning disability was asked questions first in case their responses were impacted by their family members' responses. The researcher also ensured to check back with participants with a learning disability if their relative offered an answer on their behalf, to confirm whether this was accurate for them. Despite these efforts, participants may have influenced each other and therefore the data that was collected.

Implications

The findings of the study carry a variety of implications for clinical practice, future research, and policy development.

Clinical Implications

Whilst this study cannot be considered truly representative of autistic people with a learning disability due to the qualitative approach and small sample size, the findings do suggest that participants were broadly in favour of autism being assessed even in adulthood. Moreover, the interviews yielded important data on how learning disability services might design their assessment pathways. Below follows an account of what 'good practice' would look like.

Due to the high prevalence rates of co-occurring autism and learning disability and the increased risk of delayed or misdiagnosis within these populations, learning disability services should consider implementing routine screening (for example, including this as part of assessment appointments for new referrals). When offering autism assessments, services should have transparent conversations regarding the potential benefits and anticipated consequences of diagnosis with clients and their families, including what support is offered post-diagnostically from health and social care services. This will help inform the expectations of clients and families regarding the ongoing care that they receive. This could include education on autism as a neurodevelopmental condition to address any misconceptions regarding treatment. Prior to assessment, services should also orientate clients to what assessment appointments will involve in order to manage anxieties. As part of this, clients and their families could be supported to plan around assessment appointments and consider any accommodations that may need to be made. Following diagnosis, clinicians can assess clients and their families to determine their post-diagnostic psychological needs. For example, they may benefit from education to alleviate feelings of blame or guilt, and/or support to process the delay of their diagnosis. Services should facilitate or signpost clients to organisations where they can connect with other autistic people or relatives of autistic people; specific groups for people with a learning disability may be more beneficial due to the differences this population experience. As self-esteem plays a pivotal role in identity formation, strength-based interventions will be of benefit as well as the normalisation of difference. Education and guidance may enable family members and carers to integrate the autism diagnosis into the support that they provide.

Further recommendations given by the participants in this study for services and people that support autistic people are included in Appendix M. Overall, the findings of the study support the need for greater post-diagnostic service provision; this gap also applies to

mainstream autism assessment services which tend to discharge following assessment (Norris et al., 2025).

More generally clinical services could facilitate more training regarding autism and learning disability and how these interact within relevant settings such as hospitals and schools to improve education and identification. Clinicians and clinical services must also be mindful of the language that is used when referring to neurodevelopmental conditions, to promote the normalisation of neurodiversity and neurodivergent conditions, reduce stigma, and shift discriminatory wider societal attitudes. Clinicians can challenge and model ways to talk about difference to support this. Services can also consult with Flower et al.'s (2025) research in which seven principles of neurodiversity affirming practice were co-developed with autistic adults.

Research and Policy Implications

As highlighted by some participants, this study points to the need for autism assessment tools specifically designed for people with a learning disability, as current instruments are intended for those without a learning disability. This may be problematic, as people with a learning disability often have different needs from the general population (Barrington et al., 2025). Further research is needed to explore this finding; if confirmed, additional research will be required to develop assessment tools that are valid and reliable for this population. More research is also required to identify the additional needs that autistic people with a learning disability have, to ensure they are offered appropriate support and interventions. This is particularly important given this population is at greater risk of mental and physical health difficulties and unequal access to healthcare. This study demonstrates that people with a learning disability can participate in research and provide valuable contributions. Due to the commonality and nuances of co-occurring learning disability and

autism, greater inclusion of people with a learning disability is essential in autism research as well as within coproduction of services and healthcare policy. NICE autism guidelines include sections for people with a learning disability, however specific guidance regarding this population may be more beneficial to ensure differences are accounted for to achieve optimal health outcomes for this marginalised population.

Summary of Recommendations

Based on the study findings, recommendations include:

1. Implementation of routine autism screening in learning disability services.
2. Comprehensive conversations regarding the potential benefits and consequences of autism assessment.
3. Support in preparing for autism assessments as required.
4. Post-diagnostic intervention including education, therapy, and signposting as required.
5. Delivery of autism training to appropriate external settings such as special educational needs schools to support earlier identification.
6. Application of neuro-affirmative practice including the use of purposeful language and implementation of required adaptations.
7. The development of bespoke autism assessment tools for people with a learning disability.
8. Inclusion of autistic people with a learning disability in autism research.
9. Co-production in service development with autistic people with a learning disability.
10. Inclusion of autistic people with a learning disability in autism policy.

Dissemination

The dissemination of research is integral to ensure its visibility and achieve social and political impact (Marín-González et al., 2017). To do so effectively consists of identifying target audiences and devising a plan to ensure research findings reach these (Wilson et al., 2010). Sharing the findings of this study felt particularly important given the significant lack of autism research including people with a learning disability. The researcher also felt a duty to the participants to share their feedback given they volunteered their time to participate.

As outlined in Chapter Three, a dissemination plan was developed in order to publicise the study findings. This involves different avenues of dissemination to achieve both clinical and academic impact. Firstly, at the end of each interview participants were offered to be sent a summary of the findings on completion of the project. Research has found that when research is relevant, participants would like study results to be made available to them (Shalowitz & Miller, 2008). Every participant accepted this offer, and the researcher noted their preferences for this to be shared via post or email. An easy-read version was developed for participants with a learning disability; this can be found in Appendix N. A summary of the results was also developed for family members; this can be found in Appendix O. Given that people with a learning disability experience marginalisation and benefit from belonging, as is innate to being human (Jansen-van Vuuren & Aldersey, 2020), the researcher also thought learning of other people's experiences that may be similar, could be of therapeutic benefit for participants.

The recruiting NHS learning disability service was felt a primary target to achieve clinical impact as they ongoingly complete autism assessments. To achieve this, a plan has been agreed for the researcher to give a presentation to the service to share the study findings. Presentation materials will be shared with the service, as well as specific recommendations

that participants gave for services and people that support autistic people (Appendix M). The research will also be shared with other relevant NHS services as appropriate.

To disseminate the research on a wider scale, the researcher intends to publish the research in relevant academic journals. This may include the Journal of Learning Disabilities and the Journal of Autism and Developmental Disorders. The research will also be shared with relevant organisations such as the British Psychological Society (BPS) and the appropriate faculties such as the Division of Clinical Psychology Faculty for People With Intellectual Disabilities, and at relevant conferences such as the Faculty for People with Intellectual Disabilities Annual Conference (BPS), the Annual International Academy for Research in Learning Disabilities conference, and the British Institute of Learning Disabilities (BILD) conference, as opportunity allows. Lastly, this thesis will also be available on the University of Essex Research Repository following the completion of the Doctorate in Clinical Psychology. Through dissemination, the researcher hopes to start filling the gap in literature on autistic people with a learning disability and provide a foundation for further research in this population.

Self-Reflexivity

As well as considering the role of the researcher and their influence on research processes, self-reflexivity should include how the researcher themselves has been affected (Finefter-Rosenbluh, 2017). As this section consists of my reflections, the remainder of it will be written in first person.

As mentioned in Chapter Three, I have kept a reflective log throughout the entirety of the project to note down my thought processes and wonderings. This has included the duality of my position; I am a practicing clinician as well as a researcher. I noticed how this played a

role whilst I was interviewing participants. As I spend the majority of my time in clinical practice, I am more used to interviewing people in a clinical capacity, for example during assessment sessions. Within this I exercise therapeutic skills such as paraphrasing, summarising, and sharing reflections to draw links. At times I felt the urge to do this within research interviews and consciously restrained myself to remain within my position as researcher. I felt my clinical skills came to good use when attempting to build rapport with participants to put them at ease and ensure I obtained quality data, and I could use my curiosity to prompt participants to expand on their answers. I did however sense a slight blurring at times, for example when autistic participants introduced topics that they are interested in unrelated to the topic being discussed, I noticed family members appeared uncomfortable that their relative had 'gone off track' and wanted to reassure participants that this was acceptable from my stance as a clinician.

Conducting this research has also impacted my role as a clinician. Through completing this thesis, I have learnt more about autism and perspectives on neurodivergence. I feel an increased confidence in working with autistic people and people with a learning disability and making accessible materials which will benefit my clinical work with all clients. It has made me more aware of the necessity of making appropriate accommodations during therapy and I have found myself asking clients more about this within my clinical practice. I am also more mindful of how the majority of assessment tools including neuropsychological tests and psychometric measures have been devised on certain populations; therefore caution must be used when utilising these. I am increasingly conscious of the language I use regarding neurodivergence and diagnostic categories, ensuring I frame differences as they are instead of difficulties, and I have found myself encouraging others to do the same. As part of this I am mindful not to invalidate the challenges neurodivergent people face existing in systems not built for their needs. I have noticed an increase in clients

and colleagues talking about neurodevelopmental conditions which provokes conflicting feelings in me. I think it is important to increase awareness of difference; however, I also experience scepticism as I have learnt of private assessment services that receive finances depending on the rates of diagnosis they offer. I have been wondering what people obtain from being diagnosed and what the wider issues are that are driving this need.

Completing this project has increased my confidence in conducting research, which has also transferred to completing service evaluations. I am more motivated to include and encourage others to include people with a learning disability in research and service development initiatives, as I have been angered by how much this population is excluded and marginalised. I have also become more aware of and therefore able to challenge by own ableist assumptions; I expected research interviews and quotes to be lengthy, assuming this reflected quality, when in fact it reflects participants that use a lot of verbal language which is neither superior nor inferior to those that don't. Another learning point for me is the importance of collecting participants demographic information; when writing my results I was regretful I had not recorded other participant characteristics such as ethnicity, employment status, and relationship status. This would have allowed for greater consideration of the context in which participants live, which could influence the impact of autism diagnosis and for differences between groups to be considered.

It has also affected how I view my own neurodivergence. I think it has increased my awareness of other people's assumptions regarding how I should present and therefore micro judgements they share when I deviate from these. I notice a difference in those that celebrate my neurodivergent characteristics and those that do not, and how this makes me and other people feel. This has made me think more about how I have grown up in a world unobliging to some of my needs which has naturally impacted my self-esteem. However, completing this project, reading relevant literature and interviewing autistic people, has provoked a healthy

desire in me to show myself, to model difference, and realise that dissatisfaction with difference is not my problem. As someone who questions the existence of medical categorisations of different types of neurological functioning, I can see how diagnosis can enable a sense of solidarity and therefore confidence in people that present differently.

Conclusion

This research aimed to address a significant gap in the literature by exploring the impact that autism diagnosis can have for people with a learning disability and their families. A total of 18 interviews were conducted, and the results of the RTA constructed five main themes revealing how an autism diagnosis had impacted participants. Results showed some similarities to study findings exploring autism diagnosis for autistic adults without a learning disability, such as improved understanding and acceptance. The findings also highlighted differences people with a learning disability face, such as the support they received both historically and currently, and the applicability of autism assessment tools. The findings support the call for greater post-diagnostic intervention following autism diagnosis for those that need it. Despite contributing to the foundation of autism research which includes people with a learning disability, further research is needed for this population due to apparent differences they experience. Finally, this study provides evidence that people with a learning disability can participate in research, and it is hoped future studies will build upon this to ensure the needs of autistic people with a learning disability and their families are met.

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Appendices

Appendix A - Poster for Adults with a Learning Disability

University of Essex

research

Do you have a learning disability?

Were you diagnosed with autism as an adult?

I would like to speak to you and your family!

Hello!

I am Harriet and I am a student in Essex. I want talk to people with a learning disability and autism, and their family.

autism

Can I take part?

If you have a learning disability and found out that you have autism as an adult, you and your family can take part.

meeting

What will I have to do?

You and your family will have a meeting with me. I will ask you questions about finding out you have autism. I will ask your family how they support you.

email

How can I take part?

If you have any questions or want to take part in my research, email me on Hw23503@essex.ac.uk.

IRAS Reference Number: 342728 Date: 04/05/2024 Version Number: 1.0

Appendix B - Poster for Family Members

University of Essex

Do you have a relative with a learning disability, who was diagnosed with autism as an adult?

I would like to speak to you!

Hello!

I am Harriet and I am a Trainee Clinical Psychologist at the University of Essex. I am researching the impact of an autism diagnosis in adulthood in people with learning disabilities.

Can I take part?

If you have a relative with a learning disability, who was diagnosed with autism during adulthood, you are eligible to take part.

What will I have to do?

You will attend an interview with me, and I will ask you questions about how your relative's autism diagnosis has affected you and the support you provide.

How can I take part?

If you have any questions or would like to take part in my research, email me on hw23503@essex.ac.uk.

IRAS Reference Number: 342728 Date: 13/08/2024 Version Number: 2.0

Appendix C - Easy-read Interview Guide

University of Essex

Interview Guide

This guide includes some of the questions that I am going to ask you.

There are some possible answers under some of the questions, but you do not have to choose one of these.

Who suggested you had autism?

Your doctor

Your family

The NHS Learning Disability Team

Don't know

University of Essex

How did you feel when you found out you have autism?

Happy

Scared

Sad

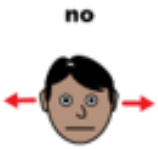
Relieved

Worried

Something else

Has anything been different since you were told that you have autism?

Yes



No

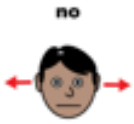
Don't know

University of Essex

If yes, what has changed?

Has your autism diagnosis changed the support you receive from family, friends or services?

Yes



No

Don't know

If so, how has it changed?

University of Essex

What was it like being assessed for autism?

Good

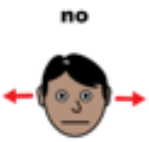
Alright

Bad

Something else

Based on your experience, would you recommend that someone else that might have autism gets a diagnosis?

Yes



No

Don't know

University of Essex

	Why is that your answer?
	Is there anything else you want to share about finding out you have autism?
	Thank you for taking part!

Appendix D - Interview Guide for Family Members

Interview Guide

- How did the autism assessment come about?
- How did you feel when you first found out your relative has autism?
- What impact has the diagnosis had?
    - On you
    - On the person with autism
    - On other family members
    - On how you understand the person
    - On how you support the person
    - On access to support services
- Has the diagnosis made a difference? How?
- What has been helpful? Have there been any unintended positive consequences?
- What has been unhelpful? Have there been any unintended negative consequences?
- Do you have any suggestions for the future/services/others?
- You can email me anything you don't want to share as a group/during the interview.

Appendix E - NHS Research Ethics Committee (REC) Approval

NHS SCOTLAND
Research Ethics Service

East of Scotland Research Ethics Service (EoSRES)

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Ms Harriet Wells
Trainee Clinical Psychologist
[redacted]

Dear Ms Wells

Study title:	**Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities**
REC reference:	**24/ES/0061**
Protocol number:	**N/A**
IRAS project ID:	**342728**

Thank you for your letter of 22 August 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, [redacted]

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

disability confident EMPLOYER

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of materials calling attention of potential participants to the research [Participant Poster]	1.0	04 May 2024
Copies of materials calling attention of potential participants to the research [Participant Poster for Family Members]	2.0	13 August 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Insurance Certificate]		01 August 2023
Interview schedules or topic guides for participants [Interview Guide for Family Members]	1.0	04 May 2024
Interview schedules or topic guides for participants [Interview Guide Easy-read]	2.0	13 August 2024
IRAS Application Form [IRAS_Form_12072024]		12 July 2024
IRAS Application Form [IRAS_Form_22082024]		22 August 2024
IRAS Checklist XML [Checklist_15072024]		15 July 2024
IRAS Checklist XML [Checklist_22082024]		22 August 2024
Letter from sponsor [Sponsor Confirmation Letter]		27 June 2024
Letters of invitation to participant [Scripts for Staff and Potential Participants (Family Members)]	1.0	04 May 2024
Participant consent form [Consent Form Easy-read]	2.0	13 August 2024
Participant consent form [Consent Form for Family Members]	2.0	13 August 2024
Participant information sheet (PIS) [Participant Information Sheet Easy-read]	2.0	13 August 2024
Participant information sheet (PIS) [Participant Information Sheet for Family Members]	2.0	13 August 2024
Research protocol or project proposal [Thesis Proposal]	1.0	01 July 2024
Research protocol or project proposal [Thesis Proposal]	2.0	13 August 2024
Response to Request for Further Information		22 August 2024
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		
Summary CV for student [Chief Investigator CV]		
Summary CV for supervisor (student research) [Research Supervisor CV [redacted]		
Summary CV for supervisor (student research) [Research Supervisor CV - [redacted]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 342728 Please quote this number on all correspondence

Yours sincerely

D Leonard.

for [redacted]
Chair

Email: tay.eosres@nhs.scot

Enclosures: "After ethical review – guidance for researchers"

After ethical review guidance for sponsors and investigators
Non CTIMP Standard Conditions of Approval]

Copy to: [redacted]

Appendix F - Health Research Authority (HRA) Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Ms Harriet Wells
Trainee Clinical Psychologist
[redacted]

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

27 August 2024

Dear Ms Wells

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities**
IRAS project ID:	**342728**
Protocol number:	**N/A**
REC reference:	**24/ES/0061**
Sponsor	**University of Essex**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **342728**. Please quote this on all correspondence.

Yours sincerely,
[redacted]

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: [redacted]

Appendix G - NHS Trust Letter of Access

[redacted]

Harriet Wells
Trainee Clinical Psychologist
[redacted]

7/10/24

Dear Harriet Wells,

Letter of access for research: Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities, IRAS 342728

As an existing NHS employee you do not require an additional honorary research contract with [redacted] We are are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. Evidence of checks should be available on request to [redacted]

This letter confirms your right of access to conduct research through [redacted] for the purpose and on the terms and conditions set out below. This right of access commences on 7/10/24 and ends on 30/9/26 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct research as per the emailed confirmation of Capacity and Capability for research from this NHS Organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received an email from us giving confirmation of our agreement to conduct the research.

You are considered to be a legal visitor to [redacted] premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through [redacted] you will remain accountable to your employer [redacted] but you are required to follow the reasonable instructions of your nominated manager [redacted] in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [redacted] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [redacted]remises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the [redacted] prior to commencing your research role at this Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

[redacted]will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend this organisation may be terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in this NHS organisation.

Yours sincerely

[redacted]

[redacted]

Appendix H - University of Essex Ethical Approval

Decision - Ethics ETH2425-0070: Miss Harriet Rose Wells

ERAMS <erams@essex.ac.uk>
Wed 2024-08-28 3:33 PM
To:Wells, Harriet R <hw23503@essex.ac.uk>

University of Essex ERAMS

28/08/2024

Miss Harriet Rose Wells

Health and Social Care

University of Essex

Dear Harriet Rose,

Ethics Committee Decision Application: ETH2425-0070

We are writing to advise you that your application to register an external ethical approval of your research project entitled "Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities" has been reviewed by the REO Research Governance Team. We are pleased to inform you that the University of Essex will accept the ethical approval granted by HRA NHS REC for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Research Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

Ethics ETH2425-0070: Miss Harriet Rose Wells

This email was sent by the University of Essex Ethics Review Application and Management System (ERAMS).

Appendix I - Easy-read Participation Information Sheet

University of Essex

Information Sheet

My name is Harriet Wells.

I am a student at the University of Essex.

research

I want to do some research for my university course.

Research is when we ask people questions to find out new information.

information

I would like to ask if you want to take part in my research.

This sheet will give you information about my research to help you decide if you want to take part.

family

I want to do research with adults with learning disabilities and autism, and their families.

autism

I want to know what it is like to find out you have autism as an adult.

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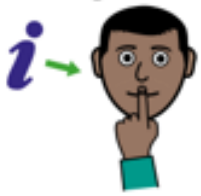
meeting	You and your family will have a meeting with me. You can meet with me separately if you and your family would prefer this.
video call	This can be in person or on a video call.
1 hour	The meeting will take about 1 hour.
ask you what you think	I will ask you some questions about your autism. I will ask your family how they help you.
answer	You do not have to answer questions if you do not want to.

University of Essex

voice recording	I will record what we talk about for my research. I will then type this up on to paper and delete the recording.
name and phone number	If you take part, I will need to know your name and your contact details. Only people that need to know who you are will be able to see this information.
information kept safe	I will keep your information safe.
anonymous 	You will be anonymous when I write up my research. This means I will not use your name.
choice	You do not have to take part if you do not want to.

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stop 	If you decide to take part then change your mind, we can stop any at time. All you have to do is let me know. I will keep the information that I already have about you.
ask questions 	If you want to know more information or have any questions, you can ask Harriet.
fill in form 	To take part, you will need to read and sign a consent form. This means you agree to take part.
email 	Email Harriet if you want to take part! Hw23503@essex.ac.uk
thank you 	Thanks for reading!

Appendix J - Participation Information Sheet for Family Members

University of Essex

Participant Information Sheet

Research Title: Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities'.

Study Sponsor: University of Essex.

Dear participant,

My name is Harriet Wells, and I am a Trainee Clinical Psychologist at the University of Essex. I am conducting a piece of research entitled 'Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities', under the supervision of Dr Anna Pettican (Lecturer) and Dr Alison Spencer (Lecturer). This research is part of my clinical psychology doctorate training at the University of Essex. This document gives you information about the study and your rights as a participant.

What is the purpose of the study?
The purpose of this study is to explore the value of receiving an autism diagnosis in adulthood for people with a learning disability. The study aims to understand how the diagnosis has impacted the adult with a learning disability and their family members. This includes exploring what the diagnosis means, how it has affected the adult and their family members, and if it has changed the way the adult is supported. To achieve this, I am inviting adults with a learning disability that have been diagnosed with autism in adulthood and their family members to attend an interview.

Why have I been invited to participate?
You have been invited to take part because you have a relative with a learning disability that was diagnosed with autism during adulthood.

Do I have to take part?
It is up to you to decide whether you wish to take part in this research study. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part but later change your mind, you can withdraw at any time by informing me. Deciding not to take part or withdrawal from taking part will have no impact on the care that you or your relative receives.

What will happen to me if I take part?
You will be invited to attend an interview with me. You and your relative will be invited to attend together, however you are also welcome to attend separately if preferred. The interview will last approximately 60 minutes. It will be arranged at a mutually convenient time. It can take place online via Microsoft Teams, or I can attend your home if you would prefer it to be in person. The interview will be recorded. If it takes place online, the built-in record function on Microsoft Teams will be used for this. If it takes place in person, a Dictaphone will be used. The interview will then be transcribed and anonymised, and the recording will be deleted.

What are the possible disadvantages of taking part?
You will be giving up approximately 60 minutes of your time to take part. Whilst this

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is not anticipated, it is possible that the interview could bring up negative emotions if you share emotive experiences. You will be provided with information regarding support services available to you, for if you feel that you require support.

What are the possible benefits of taking part?
By taking part, you will be able to share your experiences of your relative receiving a diagnosis of autism in adulthood. This research aims to further understanding of the impact and value that an autism diagnosis has for adults with learning disabilities. The findings will be shared with relevant NHS services.

How will we use information about you?
We will need to use information from you for this research project. This information will include your name and contact details, your relation to the adult with a learning disability and autism, and their name. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. You and your relatives' names will be replaced with a pseudonym to ensure anonymity. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?
You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by emailing one of the research team; Harriet Wells: hw23503@essex.ac.uk, [redacted]
- by emailing the University of Essex's Research Integrity Manager [redacted] The University of Essex's Information Assurance Manager can also be contacted on dpo@essex.ac.uk.

How will my information be stored?
All collected data will be downloaded and stored on a cloud-based, password-protected system (Box) and will only be accessible to the researcher Harriet Wells and the project supervisors Dr Anna Pettican and Dr Alison Spencer. This includes the interview data which will be in the form of a transcript. Interviews will be transcribed and anonymised and the recording will be deleted. Data will be kept secure for up to 10 years. Final anonymised data from the project may be deposited in the University of Essex Research Repository for other researchers to view. At no stage will any data be linked to any specific named individuals. Confidentiality will only be breached if concerns about the safety and wellbeing of you or other people are raised. The results

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from this study will be written up in a report for my doctorate. No identifiable information will be used within this. The findings will be shared with relevant NHS services and may be submitted for publication in a peer-reviewed journal and/or possibly shared at a research conference. You will have the opportunity to be provided with a summary of the research findings which can be sent to you.

Who has approved this project?
This research project has been given a favourable opinion by the East of Scotland Research Ethics Service (EoSRES).

What is the legal basis for using the data and who is the Data Controller?
The General Data Protection Regulation (GDPR) states that your consent must be freely given, specific, informed, and unambiguous. This will be given by you signing the consent form should you wish to take part in this study. The data controller for this study is the University of Essex and the University's Information Assurance Manager can be contacted on dpo@essex.ac.uk.

Will the use of my data meet GDPR rules?
GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules. Universities, NHS organisations and companies may use patient data to do research to make health and care better.

Universities and the NHS are funded from taxes, and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'. If they could do the research without using patient data, they would not be allowed to get your data.

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checked before this research study started to ensure that the use of your data will meet GDPR rules.

What if something goes wrong?
In the event of any issues, The University of Essex holds indemnity covers which may provide compensation for any injuries to study participants. Regardless of this, if you have any concerns or complaints about this study, then please immediately inform Harriet Wells and/or the project supervisors [redacted] (emails provided below). If you remain unsatisfied following this and wish to make a formal complaint, please contact the University of Essex Research Integrity Manager, [redacted] who will advise you further.

What now?
I would be very grateful for your participation in this study. If you have any questions and/or would like to take part, please email me on hw23503@essex.ac.uk. You are welcome to ask questions at any point. Project supervisor [redacted]

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[redacted]

Yours sincerely,

Harriet Wells
Trainee Clinical Psychologist
hw23503@essex.ac.uk

Appendix K - Easy-read Consent Form

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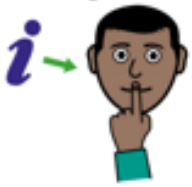
Consent Form

tick yes to all questions	Please tick each box below to confirm you agree.	
information	I have read and understand the information sheet.	☐
ask questions	I have been able to ask questions.	☐
choice	I understand I do not have to take part. It is my choice.	☐
stop	I understand I can stop the meeting if I want, by telling the researcher.	☐

IRAS Reference Number: 342728 Date: 13/08/2024 Version Number: 2.0

information kept safe	I understand what I say will be kept safe.	☐
anonymous 	I understand I will be anonymous. This means my name will not be used.	☐
research	I understand what I say will be used in research.	☐
agree	I agree to take part.	☐
write down	Please fill in the information below.	

my name	Name: ----------
date	Date: ----------
signature	Signature: ----------
Researcher Name: ----------	
Date: ----------	
Signature: ----------	

Appendix L - Consent Form for Family Members

University of Essex

Participant Consent Form

Title of the Project: Exploring the Value of Autism Diagnosis in Adults with Learning Disabilities.

Research Team: Harriet Wells (Trainee Clinical Psychologist), [redacted] (Primary Supervisor and Lecturer at the University of Essex) and [redacted] (Secondary Supervisor and Lecturer at the University of Essex).

Please initial box

1. I confirm that I have read and understand the Information Sheet dated 13th August 2024 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time by telling the researcher, without giving any reason and without my or my family members medical care or legal rights being affected. I understand that any data collected can be withdrawn until the final stages of analysis, as individual data cannot be identified beyond this point. ☐
3. I understand that whilst there is a minimal risk that taking part in the study will be distressing, it may touch on emotive topics that could be upsetting. I can confirm I have been provided with information of how I could seek support if I was to become distressed during or after taking part. ☐
4. I understand that interviews are recorded, then they will be transcribed and anonymised, and the recording will be deleted. I understand the transcripts will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
5. I understand that my fully anonymised data will be used for this project, which is being undertaken by Harriet Wells, Trainee Clinical Psychologist, as a part of doctoral training and the results will be included within a thesis research project and could be published in a research journal. ☐

6. I understand that the data collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

Participant Name	Date	Participant Signature
_____	_____	_____

Researcher Name	Date	Researcher Signature
_____	_____	_____

One copy will be provided to the participant and one copy will be kept for filing.

Appendix M – Participants suggestions for Services and People that support Autistic People

- Bond with autistic people by talking about particular topics that they like
- For there to be more education and training on autism
- For there to be a social/support group for autistic people
- For there to be a support group for parents of autistic people
- Autism assessments should take place in person
- People should get assessed for autism as early as possible
- Give autistic people more time during communication
- Be patient, be understanding and be tolerant
- For there to be specialist training for teachers in schools and colleges
- People could look at autism criteria if you suspect you/someone has it before seeking an assessment
- For the assessment to be less like a tick-box exercise
- Get to know the autistic person and family more and offer more post-diagnostic support
- Consider the learning disability more during the assessment. Have a separate section for people with a learning disability.
- Do activities such as colouring to help autistic people relax
- Get to know the persons individual needs, specifically understand their needs, their likes, their dislikes, what's triggered them, what makes them comfortable.
- Bring a pillow or a fidget toy to the assessment
- Offer more practical help
- Tell people about other opportunities outside of NHS services, signpost to other organisations and groups
- Offer support to autistic people in schools, hospitals, factories, at work

Appendix N – Easy-read Results Summary

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Results of Harriet's Autism Research

Hello, it is Harriet here!

I am a student at the University of Essex.

meeting

We met last year to talk about what it was like being told you have autism.

research

I am writing to let you know the results of my research.

interview

I completed 18 interviews in total.

This was a mix of autistic people and their family members.

write down

I read what everyone said and found there were 5 topics people talked about.

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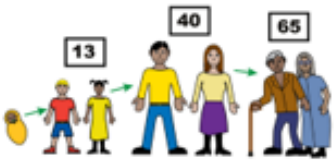
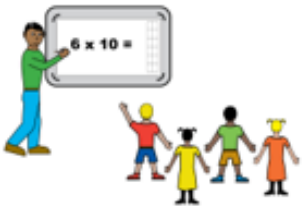
assessment	The 1st topic was about when autism was first noticed, what the autism assessment was like, and how people felt when they found out they are autistic.
age range 	Most people thought it would have been better if they had been diagnosed with autism when they were younger. Some people thought their autism wasn't noticed sooner because they have a learning disability.
school 	Some family members thought age didn't matter so much because their relative got help or went to a special school because of their learning disability.
assessment	Most people found the autism assessment OK. Some found it a bit boring or long. Some people felt nervous during their assessment.

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feelings 	People had different feelings when they found out they had autism. Some people felt relieved and happy. A few people felt shocked or angry.
understand 	The 2nd topic was about how being diagnosed with autism changed people's knowledge and understanding.
answer 	Lots of people said finding out they have autism helped them understand why they do certain things. It provided them with some answers.
autism 	Some people told me about what autism means. Some people said they find autism hard to understand.

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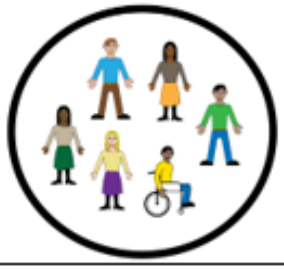
healthy mind and body 	The 3rd topic was about how being diagnosed with autism affected people's health and wellbeing.
about me 	Some people said they know who they are more and have a stronger identity now. Some people said they feel exactly the same about themselves as they did before.
	Some people said they feel more able to be themselves after their autism diagnosis. Some feel more able to unmask, stim, do things in the way they want to do them because they have autism.
group 	Some people said they have learnt about things that help them, such as fidget toys, setting routines, and social groups with other autistic people.

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my support 	The 4th topic was about how the autism diagnosis has affected the support they receive from others.
community learning disability team 	Some people said that services have helped them learn about their autism. Most people said the support they get from services has stayed the same.
family 	Some people said their families are more understanding and patient now. Some said they have stayed the same.
care 	Some people's parents said they thought autism was their fault but learned that it wasn't. Some regretted things they had made their child do before they knew they were autistic. Some felt relieved that their child had been diagnosed.

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words and text 	The 5th topic was about language and how people use or feel about the word autism.
autism 	Some people found having the label 'autism' was really helpful. Some people thought labels can make people judge others.
communication 	People said telling people they or their child has autism was a quick way to communicate why they are doing things or what they need, for example in a hospital or restaurant.
advice 	People also gave some advice and recommendations for services that help people with autism. Such as, offer more help to people after diagnosis if they need help.

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presentation 	I am going to present the results of this study to the NHS Learning Disability Service. I also plan to write it up as a research article.
ask questions 	If you have any questions after reading this, you can email me.
email 	My email address is: Hw23503@essex.ac.uk
thank you 	Thank you very much for being in my research. You have shown that people with a learning disability can take part in research!
good bye 	I wish you all the best. Take care 😊

Appendix O – Results Summary for Family Members

University of Essex

Summary of Results for Family Members

Research Title: Exploring the Impact of Autism Diagnosis for Adults with a Learning Disability and their Families.

Dear participant,

Following your participation in my research study which explored the impact of autism diagnosis for people with a learning disability and their families, I am writing to share a summary of the main findings with you. Please contact me if you would like more detailed information. Thank you again for taking part.

The Sample

A total of 18 interviews were completed made up of 33 participants. Three interviews were completed with autistic people on their own, and three interviews were completed with family members on their own. 13 interviews were attended by both autistic people and their family members or support staff. Five interviews were conducted online, and 13 interviews were conducted in person at either participant's homes or an NHS clinic. Most autistic people were between ages 20-29 and most members were aged between 60-69. All adults that had been diagnosed with autism were assessed through the NHS community learning disability service and most had been diagnosed within the last 6 months.

The Findings

The interviews were typed up into transcripts and all names were removed. The transcripts were analysed using Reflexive Thematic Analysis, which is a technique that is used for making sense of large amounts of data where themes are constructed. Five main themes and 13 corresponding subthemes were constructed, and these are displayed in the table below. A summary of each main theme is given following this.

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Theme	Subtheme
Journey to Diagnosis	Interplay with Learning Disability
	Experience of Assessment
	Initial Reaction
Understanding	Explains Behaviour
	Comprehension of Autism
Wellbeing	Identity
	Given Permission
	Learnt Strategies
Support System	Professional Input
	Treatment from Others
	Parenting
Language	Labelling
	Communication

Theme One: Journey to Diagnosis

The theme Journey to Diagnosis relates to participants' experiences of autism being identified, assessed, and diagnosed. This incorporates autistic adults' earlier life experiences including the influence of learning disability, the autism assessment itself, and how participants received the diagnosis, from both autistic people and their family members perspectives.

This theme highlights the potential impact that having a learning disability can have. Some participants suspected that autism was not identified until adulthood due to diagnostic overshadowing, in which behaviour is attributed solely to learning disability. A lot of participants felt it would have been better if autism had been diagnosed earlier, however some people felt this was not necessary as support was already in place due to the learning disability. Most participants found the autism assessment itself acceptable however it included challenges for some people, and others felt the presence of a learning disability was not adequately accounted for within the assessment. Many participants experienced relief and happiness on receipt of the diagnosis, however more difficult emotions arose for people that had not expected it. This highlights the impact that previous experiences, understanding, and the meaning that is made from later diagnosis can have.

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Theme Two: Understanding

The theme Understanding relates to how the autism diagnosis has impacted participants' understanding of themselves or their family member, influencing their wellbeing and behaviour. It also relates to participants understanding of autism itself.

This theme suggests that receiving a diagnosis of autism can increase people's understanding of themselves or their relative which has beneficial impact. However, some people shared it can make it difficult to identify whether certain behaviours are driven by autism or not. Many participants shared feeling they had little understanding of autism as a condition, suggesting some people could benefit from being supported to learn more about autism.

Theme Three: Wellbeing

The theme Wellbeing relates to how the autism diagnosis has affected the autistic individual's health, including their view of themselves and how they and others manage experiences to support their needs.

This theme suggests that for some people, receiving an autism diagnosis can create shifts in how they see and therefore feel about themselves. Some people felt it had given them a stronger sense of identity, whereas others viewed themselves in exactly the same way. For many participants being diagnosed with autism enabled greater self-esteem and confidence, meaning they felt more able to be and show themselves. Being diagnosed also helped some people learn new strategies that support their wellbeing.

Theme Four: Support System

The theme Support System refers to how the autism diagnosis has influenced the wider system around the autistic individual, impacting their and their family members experiences. This includes support from services, how they are treated by other people including their family, and ways it has impacted their family members personally.

Many participants felt the autism diagnosis had little impact on input from professional services, as the support they receive remained the same. This highlights the importance of services discussing potential consequences and expectations following diagnosis with clients prior to assessment. A lot of family members advised that the autism diagnosis led them to have more patience with their autistic relative, as they learnt certain things they do are not their fault. For others, the support that they offer their relative, or the support they received from their family member, remained the same. This theme also

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highlighted how autism diagnosis can impact family members in a caring giving role, as some participants that were parents said they had some regrets about how they had parented in the past. It gave a sense of relief to some, as they learnt certain things their relative did was due to autism as opposed to how they had been parented.

Theme Five: Language

The theme Language refers to ways that autism as a diagnostic label and word has impacted participants, through their own and others use of it, including some reflections on how participants feel about it.

Some people shared they needed or liked having a label, whereas others felt labels can lead others to stereotype people. Some participants shared the word autism helps them communicate their or their relatives' needs with others more easily, acting as a quick way to explain behaviour or access accommodations as needed.

Conclusion

The Reflexive Thematic Analysis revealed five main themes consisting of 13 subthemes, exploring the impact that receiving a diagnosis of autism can have for adults with a learning disability and their family members. This includes how it can affect autistic people and family members individually and collectively, including in their interactions with wider systems. It also includes participants' experiences across different timescales, including prior to and during assessment, and post-diagnosis. One of the most influential aspects appears to be how the autism diagnosis has altered people's understanding, leading to changes in support and wellbeing.

I will be presenting the results of this study to the NHS Learning Disability Service, along with a list of participants' recommendations for services that support autistic people. I also plan to write up my study as a research article. If you have any questions or would like more detail regarding the results, please email me on: hw23503@essex.ac.uk. Thank you again for participating.

Yours Sincerely,

Harriet Wells
Trainee Clinical Psychologist