Understanding the Experiences of Late Diagnosed Autism and Post-Diagnostic Assessment for Older Autistic Adults

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Declaration

This work has not been submitted to any other institution, or to obtain any other qualification.

Structure and Word Counts

Section One: Literature Review	
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Section Two: Research Report	
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Lay Summary

Recent research has highlighted that more people are being diagnosed with autism in adulthood, and it is no longer seen as a childhood condition. There is a growing awareness that autistic people are incredibly diverse in their presentations. Yet, many people are still missed or overlooked in childhood, struggling but going through life without an autism diagnosis. There are significant implications for people when they receive an autism diagnosis late. A thematic synthesis was conducted to explore the lived experiences of those diagnosed with autism late. Four electronic databases were searched and 16 studies were included. The results highlighted that people experience a long journey through childhood and into adulthood where they have felt different and struggled to fit in. Many experienced repeated experiences of their autism concerns being missed. The point of diagnosis was a profound moment where their difficulties and experiences were validated, and people were able to be more accepting and compassionate towards themselves. For some, they experienced strong feelings of grief and anger looking back at all the years of missed support and being misunderstood.

It is widely agreed that there is insufficient exploration of functioning within current diagnostic pathways. To overcome this, a research team at The Centre for Neurodevelopment Disorders at Karolinska Institutet have developed a post-diagnostic assessment tool using The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation. This research was conducted to explore the acceptability, usability and validity of the assessment tool with older autistic people. The results suggest that the assessment tool is acceptable and usable for older autistic people. The results highlighted some issues with validity in that there were concerns with ambiguity and some felt that the

tool oversimplified and struggled to capture the nuances of the variability of functioning.

Acknowledgements

I am especially grateful for Professor Megan Freeth, my research supervisor. Thank you for supporting me through this project. Your expertise has been invaluable, and your patience and guidance have helped me navigate the challenges of this research journey.

I would also like to thank Sven Bölte and the research team at the Karolinska Institutet for offering me the opportunity to use their tool and contribute to their vital work. I hope my findings offer useful developments and go towards supporting autistic people to receive the support they need and deserve.

Thank you to Autistica, for sharing my research and supporting me to recruit my participants. I offer a sincere thank you to my participants, this research would not have been possible without you. You generously gave your time and trusted me with your experiences. I hope I have done you justice.

I have no doubt that I could not have done this without the support of my family, especially my parents and grandma, my partner, Jonnie, who kept me grounded, and my friends and colleagues, whose laughs made the tough days lighter. To my dog, Trevor, for the companionship throughout the long days of writing. Most importantly, to my son George, for being my why.

Table of Contents

The Lived Experiences of Autistic People Undiagnosed Until Later in Life: A Systematic Review and Meta-Synthesis

Kate Johnstone (Trainee Clinical Psychologist)

Submitted as part of the Doctorate in Clinical Psychology at the University of Sheffield

Abstract

Objectives

This review aims to systematically review, critically appraise and thematically synthesise the data from existing qualitative literature which explores the lived experiences of those who received a late diagnosis of autism. Defined in this review as those diagnosed at twenty-five years old or above. This is with the goal of improving the understanding of the lived experiences of those diagnosed late and to consider what can be done to improve early identification of autism.

Design and Method

Four electronic data bases were searched and 16 studies conducted between 2016-2026 were identified, with 151 participants across the studies. Each study was critically appraised using the relevant Critical Appraisal Skills Programme checklist. Data was extracted and analysed using thematic synthesis.

Results

Three themes were developed: being different, autism difficulties being missed and impact of the late diagnosis. Within these were ten subthemes.

Conclusions

Overall, the findings highlighted the difficult journeys that participants have been on to finally receive an autism diagnosis. The diagnosis was a profound moment of validation which also brought up emotions such as anger and grief at missed support.

Practitioner Points:

- A late diagnosis of autism can result in years of misunderstanding of difficulties and support needs, often leading to social isolation, victimisation and inappropriate intervention/support. A timely diagnosis offers individuals an understanding of themselves and promotes self-acceptance and compassion and access to the relevant support.
- Frontline professionals (e.g., GP's and teachers) play an important role in recognising autism characteristics and supporting access to assessment and diagnosis. These professionals are likely to benefit from autism training to minimise the risk of autistic traits being missed and diagnosis being delayed or missed. Ongoing professional development that includes awareness of less stereotypically autism characteristics may support professionals in this way.
- Misdiagnosis can occur when autistic traits are understood solely in the context of mental health diagnoses. Where appropriate, evidence-based autism screening tools could be used within a differential assessment, where autism is also being considered. This could work to support earlier identification of autism and avoid misdiagnosis.

Introduction

Autism spectrum disorder (hereafter “autism”) is a neurodevelopmental condition which is associated with social communication difficulties, repetitive and restricted behaviour patterns, and sensory differences (American Psychiatric Association (APA), 2013). Autism is described as a spectrum condition to consider the wide range of different presentations of autistic people. As such, no two autistic people experiences the same challenges, and the impact that their difficulties have also differs from person to person.

There has been debate about identity- verses person-first language. This is ultimately a matter of personal preference but was explored to endeavour to remain respectful. The goal of person-first language is to avoid stigmatising and dehumanisation. This appears to be favoured when referring to people with diseases or mental health conditions. However, research suggests that identity-first language is preferred by autistic people (Vivanti, 2020), and the term “autistic” was favoured by autistic adults (Kenny et al., 2016). This is because some autistic people feel that they cannot be separated from their diagnosis (Taboas et al., 2022). Following, identity-first language will be used throughout both chapters.

There is a relatively consistent estimation of around 1.1% of adults in the UK being autistic (Huang, 2020; NCCWCH, 2022; BMJ Best Practice, 2022 & NCCMH, 2023). When this is compared to the estimated prevalence of autism in children, 1-2%, this suggests that autism is underdiagnosed in adults. The UK Government has recently conducted an independent review of autism to explore the prevalence and service demands. It was reported that while epidemiological estimates appear to be stable, there has been a substantial increase in recorded diagnoses of autism

(Department of Health and Social Care, 2026). The proportions of females to males varies across studies, however, there is always a higher proportion of males diagnosed (NCCWCH, 2022; BMJ Best Practice, 2022 & NCCMH, 2023). It is generally accepted that there is a higher proportion of males diagnosed with autism. Loomes et al., (2017) reported a 3:1 ratio of males to females. Although, a proportion of the differences reported are thought to reflect that females are more effective at camouflaging and ‘fitting in’ to what is societally expected (Buckley, 2017 & McQuaid, 2022), potentially due to gender related social demands. As such, difficulties are not noticed and are therefore underreported in females. Additionally, some describe concerns that the standardised diagnostic instruments may not effectively explore autistic characteristics in females (Gould, 2017).

There are generally two perspectives when considering autism, the neurodiversity perspective and deficit-based models. In brief, the neurodiversity perspective views autism as natural variation of neurological differences and that these variations are not inherently pathological, that is, not a problem to be fixed Dwyer (2022). Deficit-based models define autism by impairments, that autistic people lack something that needs to be fixed. Research is increasingly aiming to integrate both perspectives, rather than focusing solely on deficits (Brosnan and Camilleri, 2025). For example, seeking to explore the strengths that autistic people have, as well as things that they find difficult.

Autism in adulthood is becoming more widely recognised and late diagnosis of autism is becoming more common. This is likely to be because of changes in awareness and understandings of autism, and in diagnostic processes and frameworks. There is a growing awareness publicly and academically that autism is a lifelong developmental condition, not limited to childhood and something that

children will grow out of. Attwood (2007) reported how this growing awareness has supported adults not diagnosed in childhood to seek assessment. This retrospective identification in adults often occurs when individuals encounter autistic people and resonate with their experiences, or when they are seeking an autism diagnosis for their children (Crane et al., 2018). Further, diagnostic criteria no longer describe autism as purely a childhood presentation. The consolidation of autism into autism spectrum disorder in the Diagnostic and Statistical Manual – Fifth Edition (DSM-5, APA, 2013) led to the recognition of autism as a spectrum with differing levels of difference and support needs (Volkmar and Reichow, 2012). The broadening of the framework has meant that individuals whose differences may not have met criteria previously, now do. Advances in research have also shown that historically underdiagnosed groups (e.g., women) are now being identified. For example, research into gender differences has highlighted how women and girls are more likely to mask or camouflage (Rynkiewicz, et al., 2016) and in doing so hide their difficulties and differences, making diagnosing these individuals harder (Allely, 2018). This recognition of the diverse experiences of autistic people has allowed for many individuals who were overlooked in childhood to receive a diagnosis later in life.

Despite a growing understanding and awareness of the diversity within autistic people there are still many individuals who are overlooked or missed in childhood who go on to be diagnosed in adulthood. As described previously, camouflaging and masking can make diagnosis difficult. Both are particularly common in women and girls and make early recognition of autism harder (Hull et al., 2017). Additionally, and potentially adding to the difficulties in assessing autism in women and girls, the diagnostic tools were developed based on early research which involved primarily male presentations. Females often present differently, leading to

late or even missed diagnosis (Lia et al., 2015). Further, autism can be misattributed to, or co-occur with other conditions (e.g., anxiety) which can delay recognition of autism (Happé and Frith, 2020). Socioeconomic and cultural factors also need to be considered when thinking about barriers to autism diagnosis. Dosreis et al., (2006) report how individuals may have limited access to the specialist services required to seek a diagnosis. Further, waiting lists are often lengthy and individuals have to have sufficient financial resources to be able to seek a diagnosis outside of the NHS. Additionally, from a cultural perspective, different cultures have different interpretations of behaviour. Given that autism is diagnosed based on variation from the 'norm', different behaviours may be more or less salient in different cultures (Fani et al., 2026).

There are varying definitions within the research as what constitutes a late diagnosis. Some refer to late as a diagnosis received post 18 (e.g., Porthukaran et al., 2026), whereas others suggest post 35 (e.g., Ward et al., 2026). It is acknowledged that ultimately this is opinion and age 25 was selected to reflect that developmentally it is widely recognised that mid 20's reflects a transition to full adulthood, especially from a neurodevelopmental perspective (Giedd, 2004). Additionally, including participants post 25 years ensures that the research captures individuals who were diagnosed after the time when autism is typically identified.

There are significant implications for individuals when they receive a diagnosis of autism late. Firstly, research suggests there is a shared experience of relief at finally understanding their differences, validation of their experiences and emotions and new self-understanding (Gellini and Marczak, 2024 & Superson et al., 2025). Post-diagnosis, individuals often report increases in kindness towards the self and less self-criticism (Wilson et al., 2023). This was attributed to the diagnosis

offering an understanding of earlier life difficulties. This allows individuals to reframe previous struggles and experiences that were previously seen as a failure. Instead, these start to be seen as understandable considering unrecognised neurodiversity (Gellini and Marczak, 2023). This has been found to be a healing but also confronting experience (Green, 2024). This greater self-compassion was particularly present in women who had spent their life masking (Wilson et al., 2023). For some, an adult diagnosis prompts a reconstruction of their identity whereby autism is integrated into their life story and self-concept (Wilson, 2023). The above experiences are largely positive, however that is not always the case. For some they experience grief for the lack of support they received earlier in life (Gellini and Marczak, 2023). Some research highlights that this is in relation to bullying or exclusion experiences which could have been avoided had their autism being understood sooner (Lupindo et al., 2023). The above highlights the importance of timely diagnosis to reduce experiences of feeling misunderstood, grieving what could have been, and to reduce self-blame and criticism and increase compassion and understanding.

This review seeks to assimilate qualitative, lived experiences of autistic people diagnosed later in life. The review allows for first-person perspectives of autistic people to be presented, from a population of people who may have often been overlooked. It will allow for a nuanced understanding of experiences of a late diagnosis to be explored and presented. This is important given that there is a growing population of late diagnosed autistic people. This review should help to bring together what is currently known about this growing but under-recognised population and potentially highlight helpful future research. Further, autistic people diagnosed late often describe different life trajectories to those diagnosed in childhood (e.g.,

years of masking and misdiagnoses) which this review will bring together to better understand. This review is also important due to the mental health implications of receiving a late diagnosis and synthesizing the research exploring the lived experiences of such should help improve the understanding of how the timing of a diagnosis impacts wellbeing, which has implications for post diagnostic support and service development. Additionally, the review could work to highlight systemic barriers to earlier diagnosis and suggest or inform improvements to current diagnostic pathways. Exploring autistic peoples experience in this way reflects a shift away from a deficit focus and instead frames autism as something to be understood, not fixed, which hopefully works towards reducing the stigma around autism.

This review aims to fill a gap in the existing literature. There is an increasing amount of research exploring the lived experiences of autistic people, including specifically of those diagnosed late. However, there has not been a review which synthesises the qualitative research exploring the lived experiences of those who received a diagnosis late. This research aims to explore the phenomenological lived experiences of autistic people who were diagnosed late, both pre and post diagnosis. That is, their experiences of going through life without a diagnosis, and the impact of a late diagnosis, not the diagnostic assessment process itself.

Aims

The aim of the current review is to systematically review, critically appraise and thematically synthesis the data from qualitative literature exploring experiences of those who received a late diagnosis of autism. With the hopes of improving our understanding of these lived experiences, to discuss what can be done to improve the earlier identification of autism.

Method

Design

A systematic review of qualitative studies exploring the phenomenological experiences of autistic people who were diagnosed late was conducted. The data was analysed using thematic synthesis. This method was chosen to allow the assimilation of findings from multiple qualitative studies. The review reports the data using Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines (Page et al., 2021) (Appendix A). The review protocol was registered with the National Institute for Health and Care Research [NIHR], PROSPERO (reference: CRD42025630822) (Appendix B).

Eligibility Criteria

The review included studies using qualitative methods which reported primary data on the experiences of people who received a diagnosis of autism aged 25 or over. Only formal diagnoses of autism were included, that is given by a health care professional whether through the NHS or a private company. The included studies were not limited to a specific time frame or location. Other systematic reviews and syntheses were not included but were used to direct to further studies. Studies also had to be available in English. The review excluded grey literature. This was for a few reasons. Firstly, grey literature lacks formal peer review. Therefore, restricting to peer reviewed articles helped to ensure that included studies had undergone some quality control processes. It also allowed for more adequate and standardised appraisal of study quality as grey literature can often provide limited methodological detail. This can also limit reliable data extraction. Considerations were given to including book chapters detailing the lived experiences of autistic people who were

diagnosed late, however, due to the focus on exploring empirical research, these were not included. See Table 1. Below for specific inclusion and exclusion criteria.

Table 1.

Study inclusion and exclusion criteria

Inclusion	Exclusion
People with a diagnosis of autism (or variants) from a healthcare professional, diagnosed at 25 years or older	Self-diagnoses of autism
Studies that describe phenomenological experiences	Studies that describe only the diagnostic process itself
Peer reviewed qualitative studies, including mixed methods	People diagnosed with autism pre-25 years old
	Studies where it cannot be differentiated whether quotes come from those diagnosed post- or pre-25 years old
	Systematic, literature or synthesis reviews
	Studies where an English version is not available
	Studies where the full text is not available
	Studies where age at diagnosis is not reported

Search Strategy

Four electronic databases (Medline, Scopus, PsycInfo, and PubMed) were searched. This was due to their comprehensive coverage of biomedical, psychological and social literature. These databases have extensive indexing of peer-reviewed journals relevant to health and behavioural science and so maximised the chances of identifying relevant studies within this review.

One search was carried out in March 2026. Article title, abstract and/or keywords were searched on each database using the search terms described in Table 2 below. The SPIDER framework (Cooke et al., 2012) was used to develop the search strategy and adapted for each database if required. The SPIDER framework was used as opposed to other methods because it allows for researchers to capture studies which explore experiences, which was important in this review.

Table 2.

Search Strategy

Construct	Search Term
Sample: Autistic people who received the diagnosis at 25 years or older	(Autis* OR Asperger's OR ASD OR ASC)
Phenomenon of **I**nterest: Phenomenological lived experiences of being diagnosed with autism late	(Late* diagnosis OR diagnosis in adult* OR diagnosed late* OR Older adult OR Undiagnosed OR Aging OR Adult OR Ageing)
Design/**E**valuation/**R**esearch type: Studies which use a qualitative design to explore live experiences	(Experience OR perspective OR attitudes OR preferences OR interview OR group OR qualitative OR template OR narrative OR content OR discourse OR thematic OR stories)

Note. Each term was followed by AND

Study Selection

Studies were imported into Rayyan, an online platform which supports researchers in screening and selecting studies for systematic reviews. Once all were

imported, duplicates were identified by Rayyan software and checked and removed by hand by the author. The titles and abstracts of the remaining studies were screened against the eligibility criteria by the author. 10% were screened independently by the author and a peer researcher and 100% inter-rater reliability was reached. Studies were screened as eligible, not eligible or maybe. Where studies were deemed eligible or eligibility could not be determined (i.e., maybe) in the initial screening, a full text review was conducted. During the full text review, if studies were deemed not eligible, the reasons were recorded. As aforementioned, systematic reviews were not included. However, forward searches from these reviews were conducted using Google Scholar. Eligibility criteria were then applied to these studies.

Data Collection

For each study, the author, country, year of publication, method of data collection, aim, sample characteristics, qualitative methodology and findings were extracted independently by the author and arranged into a table in Microsoft Excel. Records were also kept of information pertaining to limitations of the studies, or anything else which might have impacted the results.

Quality Appraisal

Each study was quality assessed using the relevant Critical Appraisal Skills Programme (CASP, 2024) checklist. The CASP checklist was used due to providing a structured way of evaluating research evidence. This ensured that the appraisal process was consistent and transparent. It also allows for the appraisal of mixed methods studies. These studies were only appraised on the qualitative aspect of the study. The checklist consists of ten questions, each with prompts, which encourages

the appraiser to consider the validity of the results, what the results are and how valuable the research is. Quality appraisal was not used to remove articles from inclusion. Instead, it was used to consider the weight of the contribution of each study to the results.

Data Synthesis

Data was extracted from the results section of each study into Microsoft Excel and then imported into NVivo 14 (Lumivero, 2023). The data extracted included first order constructs (i.e., direct quotes reported) and second order constructs (i.e., how the authors made sense of their data). This ensured that the data was accurately considered within its context. Initial thoughts were also recorded at this time.

As described by Thomas and Harden (2008), the data was analysed using thematic synthesis methods. They describe that thematic synthesis has three stages. First, text coding done line-by-line. Next, the development of descriptive themes. Finally, the generation of analytical themes. They note that the descriptive themes are often closely related to the primary studies and that interpretation occurs in the final stage where the reviewer goes beyond the primary studies.

Rigour and Reflexivity

Researcher reflexivity is not a key component in the described steps of conducting a thematic synthesis. However, it is widely understood and acknowledged that, especially as qualitative researchers, the researchers themselves influence many aspects of research (Finlay, 2002) based on their background and experiences. Reflexivity allows the exploration of such, to ensure the integrity of qualitative research. To remain transparent, the author has reflected

on their personal and professional experiences and positionality, as documented in Appendix C.

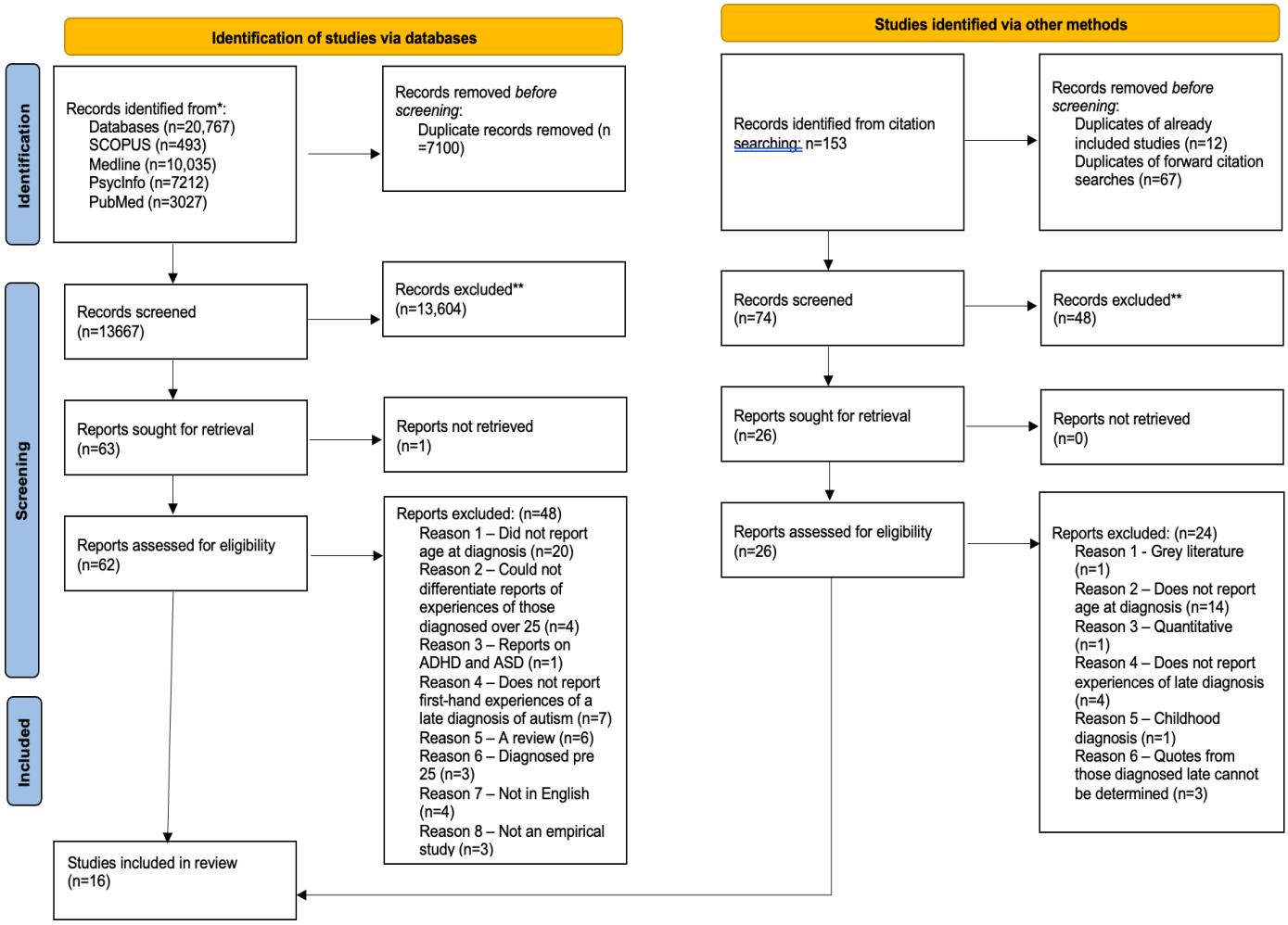
Results

Identified Studies

In total, n=20,767 studies were identified across the four databases. Prior to screening, n=7100 studies were removed as duplicates. N=13,667 studies were screened initially through applying the inclusion/exclusion criteria to the title and abstract. Following, n=63 studies remained. All 63 were sought for retrieval. N=62 studies were able to be retrieved for full text screening. The remaining study was unable to be obtained. The author made attempts to access the article. It was sought through the University of Sheffield, and through a direct request to the authors of the study. However, at the time of data analysis it had not been received and therefore has not been included. Following full text screening n=48 articles were excluded. N=14 articles remained. From the six reviews identified, forward citations searches were conducted. N=153 were identified. Following the same process as described for the primary search, duplicates were removed (n=79), and remaining articles (n=74) were screened using their title and abstract against the inclusion/exclusion criteria. N=26 studies were retrieved for full text screening. N=2 studies were included in the review. See the PRISMA diagram in Figure 1 for further detail.

Figure 1.

PRISMA diagram



Study Characteristics

Included studies were published between 2016-2026. This reflected the earliest date of an included study and does not reflect a cut-off point. Data was largely collected via semi-structured interviews, one study used free-associative narrative interviews, and another conducted oral history interviews. Data was primarily analysed using thematic analysis and interpretative phenomenological analysis, one study used framework analysis. Within the studies, 151 people shared their experiences relating to a late diagnosis of autism. These participants ages

ranged from 25-71 years old. The studies were largely conducted in the United Kingdom with the rest conducted in Japan, China, Switzerland, South Africa and Australia. See Table 3 for a summary of included study characteristics.

Table 3.

Included Study Characteristics

Author (Year)	Country	Aim	Sample and characteristics	Sampling strategy	Data Collection and Methodology	Key Findings
Harada et al., (2025)	Japan	To understand the perspective of Japanese autistic people	N=7, 4 women and three men, aged 34-46 years	Does not state	Qualitative design, analysing data from semi-structured interviews, using thematic analysis by one author under supervision of another	Three main themes identified as people feeling different and misunderstood, the search for answers, and a strong desire to be accepted
Lam et al., (2025)	China	To better understand autistic women in Hong Kong	N=3, unable to determine number of males and females, ages ranging from 30-54	Volunteer sampling	Qualitative design, using reflexive thematic analysis of semi-structured interview data	Three main themes identified as the journey leading to autism, autism diagnosis/identity being meaningful and not fitting with the autism label
Tamilson et al., (2025)	United Kingdom	Explore the experiences of autistic adults who were previously diagnoses with borderline personality disorder/emotionally	N=4, all female, ages ranging from 30-52	Purposive sampling	Qualitative design using interpretative phenomenological analysis to analyse semi-structured interview data	10 themes identified relating to struggles in early life, missed diagnoses of autism, receiving the personality disorder diagnosis, and finally

		unstable personality disorder				getting the autism diagnosis
Superson et al., (2025)	Switzerland	Expand on social and clinical understandings of autism through first hand experiences	N=4, 2 females, 1 transgender female, 1 male, ages ranging from 29-36	Purposive sampling	Qualitative design using inductive thematic analysis to analyse semi-structured interview data	Key areas identified as need for social participation, experiences prior to diagnosis, experience of the diagnostic process, life after diagnosis
Wilson et al., (2023)	United Kingdom	Exploring how an autism diagnosis influences self-compassion	N=11, all women, aged between 35-69	Purposive sampling	Qualitative design using inductive thematic analysis to analyse semi-structured interview data	Three key themes identified as disconnection between autistic self and societal expectations, unmasking and the impact of diagnosis on relationships
Ward et al., (2026)	United Kingdom	To get an understanding of the emotional and relational impact of a later life autism diagnosis	N=6, 1 male and 5 females, ages ranging from 35-65	Purposive sampling	Qualitative design using interpretative phenomenological analysis to analyse semi-structured interview data	Six themes were identified relating to positive changes, autism stigma, acceptance, missed opportunities, mental health difficulties and understanding autism

Leedham et al., (2020)	United Kingdom	Better understand the lived experiences of autistic females who received a diagnosis in middle to late adulthood	N=11, all women, aged between 44-62	Purposive sampling	Qualitative design using interpretative phenomenological analysis to analyse semi-structured interview data	Four key themes were identified as a hidden condition, the process of acceptance, post diagnostic impact and a new identity
Bargiela et al., (2016)	United Kingdom	To understand the female autism phenotype and how it links to autism in females being unrecognised	N=2 (limited because age at diagnosis was given in ranges), unable to determine gender, ages between 27-30	Purposive sampling	Qualitative design using framework analysis to analyse semi-structured interview data	Four themes were identified as you're not autistic, pretending to be normal, passive to assertive and forging a new identity
Lupindo et al., (2022)	South Africa	To contribute to the growing literature of the impact of an adult autism diagnosis in low-income countries	N=10 all male participants, ages ranging from 28-64	Purposive sampling	Qualitative design using thematic analysis to analyse semi-structured interview data	Three main themes were identified as failure to diagnose autism in childhood, impact of missed diagnosis and impact of receiving a diagnosis in adulthood
Finch et al., (2022)	United Kingdom	To better understand the lives of autistic adults	N=25 participants, 14 males and 11 females, ages ranging 27-71	Purposive sampling	Qualitative design using thematic analysis of semi-structured interview data	Six key themes were identified as diagnosis as validating yet limited, supportive and non-supportive social agents, invisibility of needs,

						health, not fitting in, and multiple lives
Stagg and Belcher (2019)	United Kingdom	Explore the lived experiences of individuals receiving a diagnosis in later life and how they experienced their diagnosis	N=9 between 52-54 years of age, 5 females and 4 males	Purposive sampling	Qualitative design using thematic analysis of free-associative narrative interview data	Five themes were identified early signs of autism, awareness of being different, receiving a diagnosis, usefulness of a diagnosis, support and coping
Hickey et al., (2017)	United Kingdom	Explore the experiences of older people with autism, particularly understanding their needs	N=13, 10 males and 3 females, ages ranging from 51-71	Purposive sampling	Qualitative design using thematic analysis of semi-structured interview data	Three main themes were identified as difference, life review and longing for connection
Powell et al., (2024)	United Kingdom	Explore the journey to diagnosis	N=5, ages ranging from 25-39. Unable to determine number of males and females	Purposive sampling	Qualitative design using thematic analysis to analyse semi-structured interview data	Three main themes were identified as journey through the diagnostic jungle, self-injury as coping and alone not abandoned
Banksgrove and Karakas (2025)	Australia	Explore the experiences of identity development in those diagnosed	N=8, 7 females and 1 individual assigned female at birth, ages from 30-59	Purposive sampling	Qualitative design using thematic analysis to analyse semi-structured interview data	Identified themes are identity formation and resources and supports

		with autism in later life				
Lilley et al., (2021)	Australia	Exploring experiences of a late diagnosis of autistic Australian people, in relation to self-identity	N=26, ages 45-72 years old, 14 females, 10 males, 1 non-binary and 1 preferred not to say	Convenience sampling	Qualitative design using thematic analysis to analyse oral history interviews	Four themes were identified as being different, exploring identity, the suffering self and being autistic
Seers and Hogg (2021)	Australia	An exploration of the impact of social and gender expectations on women's experience of autism	N=7, ages ranging from 31-53, all females	Purposive sampling	Qualitative design using thematic analysis to analyse semi-structured interview data	Three themes were identified as subverting social expectations, autism across the life span and taking control of the narrative

Quality Appraisal and Individual Contribution

Generally, the included studies had clear aims, with appropriate methodology and clear reporting of findings. Some studies were transparent in terms of considering the researchers relationship to the participants and the research process, providing positionality or reflexivity statements. However, several studies did not clearly report this or if they did there was a lack of detail. The majority of studies were transparent with regards to ethics however, some lacked significant detail in this regard, simply reporting that ethical approval had been obtained. See table 4 for a summary of the quality appraisal of the included studies which was established using the CASP checklist for qualitative research (see appendix D for a blank checklist).

Methodological limitations were considered in relation to individual study contribution. The quality appraisal process did not highlight that any of the studies had significant methodological limitations, with no substantial quality concerns. Consequently, all the studies were understood to contribute meaningfully to the meta-synthesis and differential weighting of individual study contributions based on quality was not considered to be necessary.

Table 4.

Quality Appraisal of Included Studies

Article	1*	2	3	4	5	6	7	8	9	10
Harada et al., (2025)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lam et al., (2025)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Tamilson et al., (2025)	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes
Superson et al., (2025)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes
Wilson et al., (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Ward et al., (2026)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Leedham et al., (2020)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Bargiela et al., (2016)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Yes

Lupindo et al., (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Finch et al., (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Stagg and Belcher (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hickey et al., (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Can't tell
Powell et al., (2024)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Banksgrove and Karakas (2025)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Powell et al., (2024)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Lilley et al., (2021)	Yes	Yes	Yes	Can't tell	Yes	No	Can't tell	Yes	Yes	Yes
Seers and Hogg (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes

*These numbers relate to the question numbers in the CASP Checklist for Qualitative Research

Thematic Synthesis

Thematic analysis resulted in three themes and ten subthemes. These themes reflect the prevalent experiences of participants across the data. See table 5 for themes and subthemes.

Table 5.

Themes and subthemes

Theme	Subtheme
Being Different (14 articles)	Feeling different (12 articles)
	Trying to fit in (10 articles)
Autism difficulties being missed (13 articles)	Autism difficulties overlooked, dismissed or missed (8 articles)
	Difficulties attributed to other diagnoses (6 articles)
	Lack of autism knowledge (9 articles)
Impact of the late diagnosis (16 articles)	New self-acceptance and compassion (15 articles)
	Being accepted and finally belonging (7 articles)
	Autism validating experiences (15 articles)
	Grief (5 articles)
	Anger (6 articles)

Being different

This theme describes participant experiences of feeling different from others when they were children and throughout life, and the impact that being different had. This theme also captures participant attempts to fit in and the effort it took for them to do this.

Feeling different. Across multiple studies participants described that from an early age they experienced feeling different from everyone else and never feeling as though they fit in anywhere. One participant described, "*I always felt like this alien…I*

feel like a different type of human" (Stagg and Belcher, 2019). This was mirrored by other participants, describing feeling "*like an alien"* or trying to be like others but still "*coming out like an alien"* (Lilley et al., 2021). Here, even when the participant tried to fit in, they still experienced coming across as different. There was a shared experience of feeling different and not being accepted for these differences. One participant described, "*feeling very different and struggling"* (Bransgrove and Karakas, 2025). Another described their experiences of bullying, "*owing to others perceiving them as different"* (Harada et al., 2025). Due to feeling different, one participant explained, "*I never felt like I fitted in anywhere" (*Leedham et al., 2020). Another described being "*on the outside looking in"* (Lilley et al., 2021). Being different meant that they were often excluded. One participant explained, "*I've always been an outsider"* (Lilley et al., 2021) and others related feeling different to "*feeling marginalised"* (Lilley et al., 2021). For some their experiences of being different and not fitting in were internalised with one participant explaining, "*so many people despise me, I must be a bad person".* Others described believing that they were inherently "*wrong"* and "*defective"* (Leedham et al., 2020). Being different was understood as being wrong and bad. One participant explained, "*I just thought I was really bad… I thought I was different but wrong"* (Leedham et al., 2020).

Trying to fit in. Participants across multiple studies described trying to fit in. One participant explained that their "*aim to was blend in a not appear different"* (Leedham et al., 2020). Another described that fitting in was a protective mechanism, sharing that "*hiding or mimicking… served a survival function"* (Leedham et al., 2020). A further participant described that they "*knew I could not present my true self"* (Lilley et al., 2021). These experiences describe how fitting in is seen as vital even if that means presenting as not their true self. This is most likely due to the

experiences of bullying and being excluded in response to being different, described in the previous section. Participants shared various methods of learning and trying to fit in. One participant explained that they "*learnt from various media and other people" (*Bargiela et al., 2016). Similarly, another described how they were "*obsessed with movies because they … taught me how to act" (*Lupindo et al., 2022). Another described that "*social mimicry was another strategy"* (Bargiela et al., 2016). The aim of these strategies was described by one participant as to "*outwardly become exactly like everybody else" (*Hickey et al., 2017). The above suggests that participants did not know how to behave in the ways that others do and instead had to put real effort into learning how to. Some described this process as taking on "*a performance quality"* (Hickey et al., 2017). One participant described taking "*on a persona… in order to fit in" (*Leedham et al., 2020). Participants across studies described significant implications of this whole process. One described identity issues, they explained, "*I just didn't know who I was" (*Lilley et al., 2021). Here, in trying to be like others and fit in they felt that they lost who they truly were. Another participant described "*feeling deeply unhappy and exhausted" (*Leedham et al., 2020). Additionally, unsuccessful attempts to fit in led to participants holding beliefs that they were "*wrong, broken or bad" (*Leedham et al., 2020).

Autism difficulties being missed

This theme reflects how for many participants their difficulties were present but for various reasons, they were missed or dismissed. There were three subthemes within this theme: autism difficulties overlooked and dismissed, lack of autism knowledge and difficulties attributed to other diagnoses. This meant that receiving their diagnosis was delayed.

Autism difficulties overlooked and dismissed. Across most studies participants experienced that their difficulties were overlooked or dismissed by professionals, including teachers, and sometimes family members. Participants described their "*autistic difficulties being ignored",* that they were "*not noticed"* and that "*their GP's dismissed their concerns and did not offer further assessment" (*Bargiela et al., 2016). This was a shared experience with participants here, "*the underlying cause of these challenges, being ASD, appeared to be overlooked" (*Lupindo et al., 2022). This invalidates their experiences, minimises their difficulties and limits their options in exploring a diagnosis. One participant described a sense of almost giving up for being overlooked so often, they explained, "*I was so used to being mistaken by others, misinterpreted, misunderstood; I thought, well, sod it" (*Hickey et al., 2017). One participant explained that not only were their difficulties overlooked, but they were also blamed on themselves. They described "*teachers who either blamed them for being difficult" (*Lam et al., 2025).

Lack of autism knowledge. Multiple studies described that there was a significant lack of knowledge about autism from professionals and others around the person. This was one of the reasons that autism was missed. One reason for this was a specific lack of understanding of how autism presents in females. One participant described that their teachers "*had little knowledge of female ASC"* (Bargiela et al., 2016). Autistic behaviours in young girls were misinterpreted. One participant explained, "*passive and compliant behaviour had often been misinterpreted as being 'shy' or 'good'"* (Bargiela et al., 2016). It may also be the case that because the behaviours were not problematic for the teachers, they were not seen as part of a potential autism diagnosis. Or their behaviours were not problematic enough to warrant further exploration. One participant described how

"*an individual's autism may be rendered invisible by a prioritisation of academically ability over awareness of other challenges experienced"* (Finch et al., 2022). Another participant shared similar, explaining that "*concern was dismissed by teachers and parents due to her good grades"* (Harada et al., 2025). There appeared to have been a persistent misunderstanding regarding autism in that individuals who achieved highly academically could not be autistic. Another misconception was described by one participant, explaining "*even if they appeared "more verbal", they might still struggle with social communication".* Here, the participant experienced dismissal because they had a good verbal ability. This could indicate a lack of awareness that autism is a spectrum disorder, and individuals can present very differently. One participant explained, "*a lack of autism awareness among professionals – leading them to overlook its spectrum nature, in favour of traditional stereotypes" (*Tamilson et al., 2025). Another described that "*stereotypical conceptions of autism (limited to… male clinical prototypes)"* where held by many professionals. Therefore, females or anyone who presented differently from this presentation would be dismissed. This also worked against young boys. One participant described that "*challenges were often discounted as just "boys being boys"* (Lupindo et al., 2022).

Difficulties attributed to other diagnoses. This subtheme reflects another reason why autism is dismissed or overlooked. There was an understanding across some studies that autism difficulties were overlooked by other comorbid conditions. One participant explained that "*their concerns were overshadowed by their other conditions and overlooked by clinicians" (*Lam et al., 2025). It was described that professionals may have "*prioritized their other comorbid conditions… rendering their autistic characteristic and needs overlooked" (*Lam et al., 2025). This was especially apparent for people who already had other diagnoses. When they sought help for

autism related difficulties, their concerns were overlooked in light of other diagnoses. One participant explained that "*they knew the suggested diagnoses did not adequately describe or help them"* (Leedham et al., 2020) yet their concerns were still dismissed. It appears there was a tunnel vision effect which limited the professional's ability to see beyond a diagnosis they believed accurately described their difficulties. One participant described, "*he started diagnosing me with OCD and I said, wait a minute, that doesn't fit"* (Lupindo et al., 2022). For those with self-harming behaviours they were often diagnosed with a personality disorder. One participant described, "*due to self-harming incidents, it might be an easier way of explaining things for professionals"* (Powell et al., 2024). It was felt that a personality disorder diagnosis was an easy way to explain their difficulties, despite it not fitting with how the individual understood themselves.

Impact of a late diagnosis

This theme reflects the impact that receiving a late diagnosis has, both positive and negative. Within this theme is there are five subthemes which reflect new self-acceptance and compassion, being accepted and finally fitting in, autism validating experiences, grief and anger.

New self-acceptance and compassion. This subtheme reflects how the diagnosis brought new feelings of self-acceptance and compassion. One participant described how they were able to "*unmask"* (Bransgrove and Karakas, 2025). Another explained that they could now be their "*authentic selves"* (Tamilson et al., 2025). There was an acceptance that they are "*wired differently… but not a failure"* (Bransgrove and Karakas, 2025). Another participant explained that the diagnosis "*served to reduce shame"* (Hickey et al., 2017) with self-acceptance and compassion

taking its place. This experience was shared with another participant explaining "*I can be proud of who I am, I don't have this shame anymore"* (Lilley et al., 2021). One participant described that "*difference was in fact neurodiversity and something to celebrate"* (Leedham et al., 2020). With self-acceptance came a new confidence. One participant explained that they had "*more confidence asserting their opinion"* (Bargiela et al., 2016). Through accepting oneself, one participant described a sense of letting go, "*I'm not pressurising myself to be like everyone else"* (Hickey et al., 2017). Another shared this sentiment in explaining that they no longer "*need to hide themselves to pretend to be normal"* (Lam et al., 2025). Participants no longer felt the need to acquiesce to fit in with social norms and instead felt "*very much more free"* (Leedham et al., 2020). Self-acceptance was often followed by self-compassion through the diagnosis improving the individuals understanding of themselves. Bransgrove and Karakas (2025) reported that "*the majority of participants experienced a growth in self-compassion"*. This was shared in Leedham et al., (2020) with reports that "*many were kinder to themselves"* following the diagnosis. One participant used their self-compassion and "*reframed past experiences with a compassionate lens"* (Seers and Hogg, 2021). Another participant shared this reframing process and added that the diagnosis allowed them to "*stop blaming themselves for behaviours they previously saw as personal failings"* (Superson et al., 2025).

Being accepted and finally belonging. Many studies shared a sense of participants being accepted post diagnosis and finally feeling like they belong somewhere. One participant described that "*you're accepted. You don't have to sort of hide anything"* (Hickey et al., 2017). Here they describe acceptance of who they are, with no need to try and change themselves to fit in with others. Another

participant explained that they were "*finally accepted for who they are"* (Leedham et al., 2020). For some this looked like others finally understanding what they need. One participant described that "*he'll [husband] now take the lead in situations… whereas before he just thought I was being awkward" (*Leedham et al., 2020). One participant described how through being accepted by those close to them, they were more able to accept themselves. They explained that "*they don't perceive it as anything wrong and because of that acceptance, it kind of made it easier for me to accept myself"* (Lupindo et al., 2022). For one participant, being accepted by others meant that they no were no longer blamed for their difficulties. They described "*people don't blame you… you're not at fault"* (Tamilson et al., 2025). For one participant, having the diagnosis meant that they no longer felt alone in their difficulties. They explain, "*I didn't think there were people like me before, but I felt like there were so many"* (Harada et al., 2025). This sentiment was shared by others who described "*I belong somewhere with other people… who are like me"* (Leedham et al., 2025). There was finally a sense of fitting in with other people, which they had struggled with throughout life.

Autism validating experiences*.* Overwhelmingly it was described how an autism diagnosis, and learning about autism, worked to validate participants previous experiences. One participant described how it gave them the "*ability to contextualise their differences"* (Bransgrove and Karakas, 2025), giving them a new understanding of why they might have behaved in a certain way, or why they might have struggled in a certain situation. Similarly, another participant described how the diagnosis was "*an explanation for feeling throughout their lives that they were 'different'"* and how it helped to make "*sense of their experiences"* (Finch et al., 2022). Another participant explained that "*everything clicked into place"* and likened it to a "*lightbulb moment"*

(Lilley et al., 2021). Further, a participant described the diagnosis as offering a "*fitting explanation of what they had been experiencing" (*Powell et al., 2024*).* One participant described a sense of validation, "*it means there is a logical reason for my irrational behaviour and I like that"* (Leedham et al., 2020). This was a novel experience for many, who were previously searching for an understanding of their experiences. The diagnosis alleviated the pathologising of individuals difficulties.

Grief. Across studies many participants described feelings of grief in response to their late diagnosis. One participant explained that they went through a "*grieving process"* (Leedham et al., 2020). This was in relation to "*a sense of sadness for their pre-diagnosis self and the significant struggles which may have been easier had their needs been understood"* (Leedham et al., 2020). Here the grief is partly for how they have struggled through life which may have been alleviated if they had the diagnosis and the understanding of what support they might have needed. Other participants also described "*feelings of loss in terms of all the support… they could have received"* (Lupindo et al., 2022). Again, describing the grief in looking back and considering what could have been done to support them had a diagnosis been given. Another participant's grief was for their difficult experiences, they were questioning "*what trauma could have been spared?"* (Tamilson et al., 2025). Others described grief specifically around "*missed support opportunities"* (Leedham et al., 2020). It appears participants were grieving a life they could have had, had the right support been in place in light of their autism diagnoses.

Anger. Many studies reported that participants described feelings of anger post diagnosis. For one participant it was because they "*had to be good and fit in for so long"* (Bargiela et al., 2016). Here there is anger at feeling the need to conform to be seen as good and fit in when really, they are just different to others. For another

participant it was because their difficulties were never "*recognised before, never understood, never noticed"* (Bransgrove and Karakas, 2025). Here, the anger seems to be related to feeling misunderstood throughout life. This was shared with other participants especially when they considered what might have been different "*with an earlier understanding"* (Leedham et al., 2020). Another shared anger about "*missed opportunities for support"* (Ward et al., 2026). Another participant was angry with professionals and their family who dismissed their autism (Lam et al., 2025). One participant described how they previously blamed themselves but with the diagnosis, this shifted "*to anger towards people that had been unkind"* (Wilson et al., 2023).

Discussion

The aim of the current review was to systematically review, critically appraise and thematically synthesis the data from qualitative literature exploring lived experiences of those who have received a late diagnosis of autism. Three main themes were developed through the thematic-synthesis: ‘being different’, ‘autism difficulties being missed’ and ‘impact of the late diagnosis’. The studies came together to describe a long journey through childhood and adulthood where participants felt different, misunderstood, and struggled to fit in. For many, following recurrent experiences of autism concerns being missed, diagnosis was a profound, validating moment where their difficulties and past experiences could finally be understood through a new, more compassionate and accepting lens. They finally found a sense of belonging. Yet, for others, there was a strong emotional reaction to the diagnosis where feelings of grief and anger arose at what could have been.

These experiences are consistent with the existing literature. Goodall (2021) found that autistic children had similar experiences of feeling isolated and misunderstood at school. This review adds that those who were diagnosed late and were therefore without a diagnosis at school, share this experience. This could work to suggest that this is a universal experience for autistic people, whether or not the diagnosis is known. Fusar-Poli et al., (2022) found that participants with “*average to above average cognitive abilities”* and with minimal support needs were more likely to be diagnosed in adulthood. These findings are supported by the current review in that participants described that autism concerns were overlooked in light of their academic ability and level of support needs. The review goes beyond this by adding the nuance that this was because for some professionals, higher academic ability

and autism appeared to be mutually exclusive. Further, that for someone to be seen as autistic, their difficulties had to have been sufficient and problematic enough. If not, they were not considered in the context of autism. Diemer (2024) found that having more previous diagnoses was associated with a later age at diagnosis. Again, consistent with the findings of this review where participants reported that often autistic concerns were overshadowed by other diagnoses. The review adds context to these findings in working to explain that this was because professionals put higher priority on existing conditions in a tunnel vision effect where autism concerns were quickly dismissed. Further, some felt that other diagnoses were an easier way of explaining difficulties, which led to autism being dismissed. Allely (2018) and Hull et al., (2017) both found that women and girls are more likely to mask their difficulties and that this makes it harder to diagnose these individuals. This is consistent with this review, although this review also found that males were described to mask. This indicates the importance of not assuming that masking is just a female phenomenon. Gellini and Marczak (2024) found that late diagnoses of autism validated people's experiences, offering a new self-understanding. The current review extends this by describing the impact that this new understanding had on increasing self-acceptance and compassion.

The findings of this review lend weight to the Social Model of Disability (Oliver, 2013) in which it is described that people are disabled by societal barriers, and less so by a condition. Participants described receiving a diagnosis as a profoundly validating and affirming experience, despite no change in their difficulties. This supports the Social Model of Disability by suggesting that their distress may stem less from autism itself, and more from trying to fit into a neurotypical world with lifelong experiences of being misunderstood and overlooked. When they received

the diagnosis and were able to let go of what society expected, there was a sense of freedom and acceptance. The diagnosis offered many the realisation that it was societal expectations that were the ‘problem’ and not themselves and their autism. The fact that a diagnosis was such a profound moment, even though their difficulties had not changed as a result, supports the idea within this model that the ‘problem’ lies, at least in part, outside of autism. The findings also support the Neurodiversity Paradigm (Dwyer, 2022) which proposes that autism, and other neurodivergences, are natural variations in human brain development, rather than difficulties to be pathologised and fixed. In line with the paradigm, participants described that the diagnosis allowed them to reframe previous feelings of failure as differences rather than deficits. They no longer felt like a problem to be fixed, instead diagnosis facilitated self-acceptance and compassion. Supporting both models, diagnosis did not change them or the difficulties they experienced but changed how they understood themselves, with a significant impact.

The review is also consistent with literature which explores other neurodevelopmental conditions. Ginapp et al., (2022) found that people diagnosed with ADHD in adulthood shared similar themes around feeling different, initial misdiagnoses, changes in self-acceptance and a wish for having been diagnosed sooner. This suggests that not being identified as neurodivergent until later in life has a similar impact regardless of the specific condition. It could also lend more support to the Social Model of Disability, in suggesting that difficulties arise more from an incongruence between the individual and their environment, and less from their neurodivergent traits. It also suggests that societies response to difference is similar, regardless of what the differences are.

This review has important implications. GPs and other professionals, including teachers, were reported to overlook autistic concerns, with participants sharing that professionals had a lack of awareness of autism. This has implications for diagnostic pathway access. It may indicate a need for training for frontline professions in being able to recognise, particularly less stereotypical presentations of autism. This could involve supporting professionals to become aware of their own preconceptions of autism. There should be a focus on the spectrum nature of autism so that less common difficulties that may deviate from a stereotypical presentation are not overlooked. The difficult experiences that participants experienced throughout their life prior to diagnosis highlight the importance of a timely diagnosis. Supporting the need for increased awareness in frontline professionals. Improving professional understanding and awareness of autism should work to support earlier recognition and reduce these experiences. Additionally, some participants reported having other mental health diagnoses which overshadowed autism concerns. This suggests a need for more improved screening for autism within mental health services to hopefully avoid misdiagnoses.

This review is a thematic meta-synthesis. A strength of this is that it retains the lived experiences of participants, which is particularly important in autism research where the voices, especially over those diagnosed late, are underrepresented. It keeps the real experiences of the participants at the centre of the research. It also allows for commonalities and differences to be captured across studies which may involve different groups of participants. There are also potential limitations. It is a synthesis of a large size of research output so it is almost inevitable that some detail will be lost from the original studies. Additionally, as with all thematic analyses, the derived themes depend on the authors interpretation. This is not seen as inherently a

flaw within thematic analysis. However, it does mean that another researcher might have organised themes differently, and prioritised different details.

A potential limitation of the review is that a broad research aim was used. This was considered appropriate given that lived experiences of late-diagnosed autism are relatively under researched, allowing for the review to capture a wide range of lived experiences. It follows that a larger number of themes were developed, which reflects the complexity and variability of the participants experiences. Breadth versus depth was considered and it is acknowledged that ultimately some depth will have been lost to ensure that the participants experiences were comprehensively and coherently described. Future research could explore specific aspects of receiving a late diagnosis to be able to offer a more in depth understanding of more specific experiences. Research to understand the longer-term impact of a late diagnosis would be beneficial, as would research exploring what kind of support late diagnosed autistic people would find helpful in managing the processing of coming to terms with the diagnosis.

Typically, two independent reviewers undergo a proportion of the included study quality appraisal to minimise bias and support reliability. Due to time and resource constraints associated with this doctoral thesis, this was not possible and quality appraisal was only conducted by the lead researcher. Following, this is a methodological limitation. However, using CASP checklists ensured that the quality appraisal was as consistent and objective as possible.

Many of the included studies focused on the experiences of women. This may reflect that females are more likely to be diagnosed late, and therefore, more research includes females. This is not considered inherently problematic given that

females are largely underrepresented. This review highlights that and works to fill this gap and give these perspectives a voice. However, it means that this review may describe more of the female experience and not fully reflect the experiences of late diagnosed autistic males. A scope for future research could be exploring late diagnosis in males and comparing that to female experiences.

Conclusion

The review aimed to systematically review, critically appraise and thematically synthesise research which explores the lived experiences of receiving a diagnosis of autism late. The review brought together the existing literature pertaining to lived experiences of receiving a late diagnosis of autism. The findings highlighted the journey of struggle that individuals go through without a diagnosis when their difficulties are missed or overlooked. Receiving a diagnosis was a complicated moment of validation accompanied by feelings of anger and grief at what could have been. The review has clinical implications in highlighting the importance of improving professional awareness of less stereotypical presentations of autism to reduce the occurrences of autism being missed or overlooked.

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Appendices

Appendix A

PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 9
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Guidance followed
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 16-17
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 17
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 18- 19
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 19-20
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page19-20
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 21
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 21
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 21-22

Section and Topic	Item #	Checklist item	Location where item is reported
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 21
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 21-22
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 21
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 22
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 22
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Page 32
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N\A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 24-25
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 25
Study characteristics	17	Cite each included study and present its characteristics.	Page 27
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 33
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N\A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 32
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N\A

Section and Topic	Item #	Checklist item	Location where item is reported
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N\A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N\A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N\A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N\A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 45
	23b	Discuss any limitations of the evidence included in the review.	Page 50
	23c	Discuss any limitations of the review processes used.	Page 49
	23d	Discuss implications of the results for practice, policy, and future research.	Page 48
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 18
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 18
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N\A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N\A
Competing interests	26	Declare any competing interests of review authors.	N\A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendices

Appendix B

Prospero Registration

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

The lived experiences of autistic people undiagnosed until later in life: a systematic review and meta-synthesis

Kate Johnstone, Megan Freeth

Citation
Kate Johnstone, Megan Freeth. The lived experiences of autistic people undiagnosed until later in life: a systematic review and meta-synthesis. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42025630822

REVIEW TITLE AND BASIC DETAILS

Review title
The lived experiences of autistic people undiagnosed until later in life: a systematic review and meta-synthesis

Review objectives
1. To systematically identify qualitative research that explores the lived experiences of autistic people who were undiagnosed until later in life.
2. To generate a thematic synthesis of themes in the literature reporting on lived experiences of autistic people who were undiagnosed until later in life.

Keywords
Autistic, Diagnosis in adulthood, Experiences, Late Diagnosis, Undiagnosed

SEARCHING AND SCREENING

Searches
The search for primary studies will be conducted on PsycINFO, PubMed, MEDLINE and Scopus.
One search will be carried out between February 2025 and May 2026.
Papers will be chosen based on inclusion criteria (e.g., where they are written in English and the full paper is available) and there will be no restrictions on publication dates. Only published literature will be included to seek to ensure a higher level of methodological quality of included studies.
The following search terms will be included covering these 3 areas:

(Autis* OR Asperger's OR ASD OR ASC)
AND
Experience OR perspective OR attitudes OR preferences OR interview OR group OR qualitative OR template OR narrative OR content OR discourse OR thematic OR stories
AND
Late* diagnosis OR diagnosis in adult* OR diagnosed late* OR Older adult OR Undiagnosed OR Aging OR Adult OR Ageing

Study design
Inclusion: Studies that use qualitative methodology to report on and present empirical qualitative data on the lived experiences of autistic people who were undiagnosed until later in life.
Exclusion: Systematic or literature reviews, although these may be used to direct to relevant papers. Studies that do not focus on lived experiences of receiving a late diagnosis (e.g., those that report explicitly on the diagnostic process, rather than life experiences). Studies that do not contain qualitative data. Studies where the full text does not exist. Studies that are not in English.

ELIGIBILITY CRITERIA

Condition or domain being studied
Autism Spectrum Disorder (ASD)

Population
Inclusion: People who received a diagnosis of autism as an adult (25+). 25 years old was decided to be the minimum cut off age because 16-25 is often considered a transitional period from adolescent to adulthood. To illustrate, within the NHS it is when individuals transition from children to adult services. Additionally, mid-twenties are when the brain is understood to be matured, where as before, developments are thought to still be occurring. Therefore, a minimum age of 25 was thought to be appropriate. Additionally, the scoping searches highlighted that even when inclusion criteria stated adulthood, participants were primarily 25 and over.
Exclusion: People who received a diagnosis of autism under the age of 25

Intervention(s) or exposure(s)
Not applicable

Comparator(s) or control(s)
Not applicable

Context
Within autism research, much of it focuses on children. There is very little exploring experiences of autistic adults in general, especially the experiences of those who have gone through life undiagnosed until adulthood.

OUTCOMES TO BE ANALYSED

Main outcomes

To systematically review qualitative research which explores the lived experiences of autistic people who were undiagnosed until later in life through the researchers applying the inclusion/exclusion criteria to relevant papers and reporting on the research findings.
To generate themes from the literature reporting on the lived experiences of autistic people who were undiagnosed until later in life through the use of thematic synthesis models.
To critically appraise the qualitative research that explores the lived experiences of autistic people who have received a late diagnosis. This will be done through the researcher gathering information pertaining to the authors, the title and journal, the study design, any adaptations to support the involvement of autistic people and limitations of the research, or any other factors that may affect the results. This will be supported using relevant Critical Appraisal Skills Program (CASP) checklists.

Measures of effect

Additional outcomes
Not applicable

Measures of effect

DATA COLLECTION PROCESS

Data extraction (selection and coding)
Studies will initially be screened through title and abstracts, however where needed full paper searches will be complete. Two reviewers will independently apply the eligibility criteria and select the studies for inclusion for the first 10% of studies. Interrater reliability will be assessed, and discussions will take place to consider any discrepancies. Discrepancies will aim to be resolved by consensus between two authors, and where necessary, the wider research team. Decisions made regarding discrepancies will be recorded on the software system Rayyan. These discussions will inform how the studies are screened which will be completed by one reviewer. Data screening will also be supported by using the software Endnote to remove any duplications.
For each study the following data will be extracted by one reviewer:
Primary data: direct quotes from autistic people who were undiagnosed until at least 25 years old.
Secondary data: Authors, title, journal, study setting (e.g., country, data, year of data collection), study design (aims, inclusion/exclusion criteria, sample size and strategy, methodology), adaptations to support inclusion of autistic people, limitations identified by the authors, any other factors that might affect results (using CASP checklist).
If any data is missing, the first author will be contacted to seek to obtain the data so that the study can be included. If not, this will be described in the write up.
An Excel spreadsheet will be used to collect the data.

Risk of bias (quality) assessment
The CASP checklist for qualitative research will be used to assess the quality of each article. One reviewer will assess the quality of the studies, and this will be detailed in the report in a quality assessment table. An independent review of 10% of the studies will be conducted and interrater reliability will be assessed and discussions had regarding any discrepancies.

Discrepancies will aim to be resolved by consensus between the two reviewers, and if necessary, the wider research team. Any decisions made about discrepancies will be described in the report.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

A thematic synthesis will be used to synthesise the findings once the primary data has been extracted. This method uses three stages. First, the data will be entered into a database (e.g., NVivo) and a reviewer will independently code each line of text according to meaning and context. Free codes will be created inductively to ensure that the meaning and content of each sentence is captured. Line by line coding will ensure that the concepts can be translated between studies. Second, descriptive themes will be developed. This involves translating the concepts from one study to another. A hierarchical structure is created by grouping based on similarities and differences between the codes. Third and finally, analytical themes will be developed that go beyond the content of the original studies. Themes will be reviewed by one researcher to consider implications, and then discussed with the wider research team. This will allow for the consideration of more abstract themes that go beyond the content of the original studies.
Secondary data will be used to assess quality.

Analysis of subgroups or subsets

Not applicable

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Miss Kate Johnstone, University of Sheffield
- Professor Megan Freeth, University of Sheffield

Review affiliation

University of Sheffield

Funding source

University of Sheffield

Named contact

Kate Johnstone. Clinical Psychology Unit, University of Sheffield Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT
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TIMELINE OF THE REVIEW

Review timeline

Start date: 03 February 2025. End date: 30 April 2026

Date of first submission to PROSPERO

06 January 2025

Date of registration in PROSPERO
06 January 2025

CURRENT REVIEW STAGE

Publication of review results
The intention is not to publish the review once completed.

The review will be submitted as part of a doctoral thesis project. Following the submission, publication may be sought through applying to relevant journals.

Stage of the review at this submission

Review stage	Started	Completed
Pilot work		
Formal searching/study identification		
Screening search results against inclusion criteria		
Data extraction or receipt of IP		
Risk of bias/quality assessment		
Data synthesis		

Review status
The review is currently planned or ongoing.

ADDITIONAL INFORMATION

PROSPERO version history

- Version 1.0 published on 06 Jan 2025

Review conflict of interest
None known

Country
England

Other registration details
Not applicable

Medical Subject Headings
Autistic Disorder; Humans; Qualitative Research

Details of any existing review of the same topic by the same authors
Not applicable

Disclaimer
The content of this record displays the information provided by the review team. PROSPERO does not peer review registration records or endorse their content.

Appendix C

Reflexivity and Positionality Statement

I, the lead researcher, am a 30-year-old neurotypical female. I recognise that this puts me in an outside position in relation to the participants in the research I am exploring. I acknowledge that being neurotypical will inevitably shape how I understand and interpret the experiences identified in the systematic review. I appreciate that as someone who does not have lived experience of autism or being diagnosed late there may be a risk that I misunderstand or place emphasis on parts of the experiences, which may be unintentionally biased towards neurotypical assumptions and perspectives. I have many years of experience working with autistic people and these experiences could influence my interpretation of the participants experiences.

Reflexivity was embedded in the research process. I made notes throughout the process pertaining to any preconceptions, assumptions and potential personal influences. These were also discussed in supervision to work to maintain my awareness of my own biases/assumptions to reduce the impact these may have had on the research. I do not claim that the research can ever be entirely objective but also do not see this as a flaw. Instead, I see the research as an interaction between myself and the participants in the research with the findings being shaped by this interaction.

Appendix D

Blank CASP Qualitative Studies Checklist

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	

5. Was the data collected in a way that addressed the research issue?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	

8. Was the data analysis sufficiently rigorous?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	Negative/Relatively poor methodology	Unknowns

Exploring the Validity, Acceptability and Usability of the International Classification of Functioning, Disability and Health (ICF) Core Sets Assessment Tool for Older Autistic People: A Mixed Method Study

Word Count: 7992

Kate Johnstone (Trainee Clinical Psychologist)

Abstract

Objectives

Autism is a lifelong neurodevelopmental condition which has a significant impact on day-to-day experiences. It is becoming widely accepted that daily functioning is not appropriately assessed in the current autism diagnostic pathways. In response to this, the ICF Core Sets for Autism assessment tool has been developed to better explore functioning. This research aimed to explore the acceptability, usability and validity of this assessment tool with older autistic people.

Design and Method

This research employed a mixed method design. Fourteen autistic adults over the age of 50 took part. Through engaging in a cognitive interview while completing the assessment tool, validity was explored. Reflexive thematic analysis (RTA) was used to analyse cognitive interview data. Next, measures of acceptability and usability were completed. Descriptive statistics were used to explore the two measures.

Results

The assessment tool was found to be acceptable and usable for older autistic people. Five themes were developed: issues with ambiguity, an assumption of ‘normal/appropriate’, cultural differences, how do I boil that down into a number? and the real me vs. my masked self.

Conclusions

It was concluded that the assessment tool was acceptable and usable for older autistic people. With regards to validity, issues were highlighted in that there were issues with ambiguity, some described that the tool was unable to capture the

nuances around the variability of functioning, and some felt that it was unable to account for cultural differences.

Practitioner Points:

- It would be helpful for the following updates to be considered. Firstly, for the introductory information to guide participants with regards to whether they should rate their reality, or their masked selves. Next, to include guidance in the introductory information about the scale, to clarify as to whether the intention is for people to rate in comparison to ‘normal’ functioning. Finally, to be able to rate items additional times to allow for rating across contexts.
- The current diagnostic process is not always thought to sufficiently explore day-to-day functioning, particularly across different contexts. As a result, important support needs may not be identified despite receiving an autism diagnosis. Introducing this tool into the diagnostic process would support a more comprehensive understanding of daily functioning.
- In identifying strengths, challenges and environmental supports and barriers, the results of the assessment may be helpful in different contexts. It could be helpful in supporting practitioners to develop comprehensive and individualised support plans. Additionally, the results could be used to guide reasonable adjustments in employment and healthcare, which could work to improve accessibility for autistic people.

Introduction

Autism is a lifelong neurodevelopmental condition associated with challenges in social communication and interaction, repetitive and restrictive behaviour and sensory differences, which cause significant functional impairments (American Psychiatric Association (APA), 2013). Globally, it is estimated that 1 in 27 people are autistic (Zeidan et al., 2021), with it being more common in males than females (Zeidan et al., 2021). This is partially attributed to females being more effective at camouflaging to social expectations (McQuaid, 2022). Refer to chapter one for a more detailed description of autism and its prevalence.

Autism is primarily understood within diagnostic frameworks (e.g., the Diagnostic and Statistical Manual of Mental Disorders – Fifth edition (APA, 2013). While there are benefits to this, there are significant disadvantages. It restricts understanding of an individual to the confines of the diagnosis (Shakespeare, 2006), overshadowing an exploration of challenges and strengths within the environmental context (Bölte, 2023). It is criticised for suggesting that autism is an individual problem, rather than acknowledging the role of the social environment (Milton et al., 2019). As a spectrum disorder, the lack of flexibility within a diagnostic framework is unable to account for this heterogeneity (Bölte et al., 2019). This is likely to lead to an inappropriate one-size-fits-all service approach. Milton et al., (2019) criticised the pathologising nature of diagnostic frameworks, where there is a focus on noticing what is not ‘normal’ about a person. In focusing on deficits (including the assumption that differences from the ‘norm’ are deficits) and ignoring strengths (Armstrong, 2010 & Milton et al., 2019), it contributes to the stigma in suggesting that autistic people either lack or have unusual behaviours (Anderson-Chavarria, 2022).

Bölte (2023) argues that assessment should not stop at diagnosis, which instead should be followed by a functional assessment. Defined as "*a person's performance arising from the interactions between their individual strengths and challenges, and the facilitating and hindering factors in a given context" (*Bölte, 2023)*,* a functional assessment seeks to understand strengths, challenges, and environmental context. Rejecting a deficit focus and providing meaningful information for services and autistic people. Existing functional assessments are often generic and neglect to explore strengths or context (Bölte, 2023). They are often only included to show that the person meets the 'impairment' diagnostic criteria. Black et al., (2025) found that common measures used in autism diagnosis only covered between 8-41% of functioning compared to the assessment tool. Research suggests that autistic people are likely to have greater difficulties in this way (Alvares et al., 2019), indicating the importance of appropriate assessment as part of the diagnostic process.

The term functioning has negative connotations for some autistic people due to its incorrect association with impairment (Bölte, 2023). It has been used to differentiate between autistic people with and without a learning disability when an individual's intellectual ability does not necessarily predict their functional skills (Alvares et al., 2019). The phrases 'low' and 'high' functioning are problematic because they come with assumptions of someone's abilities that are likely to be inaccurate when considering the true definition of the term functioning. Bölte (2023) argues for this to be put aside, so that functioning can be understood in its intended neutral form.

The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation (WHO) (2001), is a tool used to explore

functioning, consisting of nearly 1400 categories (Selb et al., 2014). To facilitate the use of the ICF in clinical practice, WHO and the ICF research branch developed a procedure for creating ICF cores sets which contain only relevant areas of functioning. Selb et al., (2014) highlight three principles which must be adhered to when developing core sets: it must be evidence based, incorporate lived-experience, professional and expert perspectives, and professionals should be from diverse disciplines. Additionally, the decision-making processes should be international, ensuring that the core sets are appropriate for worldwide implementation. ICF core sets have been developed for many physical and mental health conditions. Some core sets are used within the National Health Service (NHS) (see G-AP Framework, 2023; Stier-Jarmer et al., 2009; Schiariti, et al, 2018 and Stucki et al., 2002). The Centre for Neurodevelopment Disorders at Karolinska Institutet (KIND) have developed autism core sets and operationalized them into an online platform, the ICF Core Sets for Autism assessment tool (hereafter ‘the assessment tool’). The older adolescent and adult version includes 79 categories across the ‘activities and participation’, ‘body function’ and ‘environment’ domains. The assessment tool generates real time results, showing a person’s strengths, challenges and environmental barriers and facilitators.

Preliminary research has found promising validity for the autism core sets. Black et al., (2019) used the core sets to explore the influencing factors of successful employment for autistic adults across Australia, Sweden and the United States. They found that, across all countries, the activities and participation and environment domains were highly associated with employment outcomes, suggesting validity of use in this context. Fridell et al., (2022) found that the core sets effectively covered the lived experiences of autistic people during the COVID-19 pandemic. Viljoen et

al., (2019) explored the coresets with caregiver/parent perspectives in Sweden and South Africa. They concluded that the coresets have global usefulness and highlighted the usefulness of them in exploring unmet needs and guiding support for autistic people at university.

More recently, Freeth et al., (2026) found the assessment tool to be acceptable and usable with autistic adults from the United Kingdom. Alehagen et al., (2025a) found that the assessment tool was feasible and user friendly and was able to distinguish between autistic and neuro-typical individuals (Alehagen et al., 2025b). They concluded that the assessment tool shows diagnostic and construct validity. Further, Black et al., (2025) linked the assessment tool items with commonly used autism diagnostic assessments. They found that very few aspects were not found within the assessment tool and concluded that this provided evidence to support the validity of it.

This research aims to build on this, exploring the validity, acceptability and usability of the tool with older autistic people, which has not yet been explicitly explored. Validity can be defined as the degree to which something measures what it intends to measure. Acceptability refers to how an intervention (i.e., the assessment tool) will be received by the intended population and how well it meets their needs (Ayala and Elder, 2011). Usability refers to the ease of use of and attitudes towards a tool (Brooke, 1996). Involving autistic people is vital given many feel that within the current diagnostic model, their views are dismissed (Sarrett, 2016).

Consideration was given to ‘older’ age. Mason et al., (2022) used 50 years old to reflect older adults due to Roestorf et al., (2017) reporting that cognitive aging occurs at this age in many different areas. Croen et al., (2015) supported the use of this age as ‘older’ through highlighting that autistic people may experience an

accelerated aging process. Additionally, Hirvikoski et al., (2016) described the increased risk of premature death for autistic people due to comorbid conditions.

Autism has historically been understood as a childhood condition that people "*grow out of"* with a lack of longitudinal research to challenge this assumption (Rutter 1978). Following, the understanding of autism and support provisions have been derived from childhood data (Robinson, 2019). There is a sparsity of research exploring autism in older adults and a lack of understanding of autistic presentations and support needs of older adults (Tse et al., 2022; Sonido et al., 2020). Given that changes are seen in the general aging population (Roestorf et al., 2022), it follows that autistic people will experience age related changes, related and unrelated to autism (Sonido et al., 2020), which will impact functioning.

The Department of Health and Social Care (2021) and the NHS long term plan (2019) have prioritised improving support, outcomes, and preventing the perpetuation of inequalities for autistic people (The Autism Act, 2009; Autism Strategy, 2013). The autism core sets are cited as a potential framework that could meet the goals identified above (NHS England, 2022).

Research Aims

The current study aims to assess the validity, acceptability and useability of the ICF Core Sets for Autism Assessment Tool with autistic people who are over 50 years of age.

Method

Design

The study adopts a mixed methods design. The qualitative aspect involved using cognitive interviewing to gather data regarding the assessment tool, which was analysed using RTA. Cognitive interviewing is a qualitative technique used in questionnaire development to explore the validity of questionnaires (Meadows, 2021; Willis, 2004). Cognitive interviewing focuses on the cognitive processes involved in reaching answers to questionnaire items, seeking to understand the respondents understanding of the items, to establish whether that is consistent with that of the intent of the developer (Meadows, 2021). There are two techniques used, 'think aloud' and 'verbal probing' (Willis, 2004). Think aloud involves the respondent verbalising their thought process as they consider their answer. Verbal probing involves asking follow-up questions to the respondent after they have answered. Probes can be scripted or unscripted and presented concurrently or at the end of a section (Meadows, 2021). Cognitive interviewing techniques are also used to explore framing and directions within questionnaires, questionnaire domains, and the questionnaire as a whole (Irwin et al., 2009).

The quantitative aspect involved participants completing measures of acceptability and usability (see measures section below). Descriptive statistics are presented for both measures.

Patient and public involvement

Sheffield Autism Research Lab (ShARL) employ an Autistic Advisor who consulted on the research. Consultation was also provided from a research assistant within ShARL. They initially advised on all participant facing information, ensuring that it was accessible for autistic people. Their further input will be described in the relevant sections.

Ethics

Ethical approval was sought and obtained from the University of Sheffield Research Ethics Committee (Reference number: 057502) (Appendix A). The research complied with the university's Research Ethics Policy (2024). Prior to taking part and after reading the full information, participants were offered the opportunity to ask any questions. Following, they gave their informed consent to take part. Participants were debriefed at the end of their participation (Appendix B).

Recruitment and participants

Participants consisted of adults who had received a diagnosis of autism spectrum disorder and were over 50 years old. Participants were required to meet the following inclusion and exclusion criteria:

Inclusion criteria:

- Formal diagnosis of ASD including variants
- Over 50 years of age

Exclusion criteria:

- Comorbid diagnosis of a learning disability
- Not fluent in English

There is varying guidance on sample sizes for cognitive interview research. Some suggest that less than 25 is small (Meadows, 2021) while others suggest that 9 is considered small (Willis, 2004). Willis and Artino (2013) suggest that cognitive interview studies generally have between 10 and 30 participants and that as little as five participants can provide useful information. Considering the above and the need to be realistic within the scope of a doctoral thesis, the study aimed to recruit 20 participants. Researchers have acknowledged that sample size is dependent on the purpose of the research and time also must be considered. Twenty was considered

appropriate given that the research involves a relatively specific sample, when larger samples are required when exploring concepts across demographics, rather than within.

Participants were recruited using a purposive strategy through Autistica. A purposive strategy was used because this method is helpful when seeking participants who are most relevant to the research and to ensure the sample is representative. Autistica is considered one of the United Kingdom's leading autism research charities who advertise research through sharing adverts with their mailing list. Autistica agreed to share the advert of the present study (Appendix C). 110 individuals registered their interest in taking part. The information sheet (Appendix D) was shared with those individuals with a link to complete a screening questionnaire (Appendix E) if they wished to take part and detailing a deadline for completing the screening questionnaire, and a date by which they would be informed if they had been selected to take part. Seventy-one individuals completed the screening questionnaire. Their answers were reviewed to ensure that the individuals met the relevant criteria. 26 individuals did not provide contact information and so could not be contacted further. The remaining forty-five individuals met the criteria. To select the 20 participants the screening questionnaire was reviewed with regards to ethnicity. The aim was for 20% of the participants to be from ethnically minoritised backgrounds in line with the estimated proportions of ethnicities in the UK (Office for National Statistics, 2022). To remain fair, of the individuals from ethnically minoritised backgrounds, they were offered a place based on a first come first serve basis. The rest of the places were filled again on a first come first serve basis. The remaining individuals were asked if they would like to remain on a reserve list.

Participant demographics

Fourteen participants took part with an age range of 51-67 and a mean age of 56.14. Nine participants were female, four were male and one preferred not to say. All participants had a diagnosis of Autism, diagnosed by a UK healthcare professional. The majority of participants identified as White British (n=9), one as White Scottish, two as Black British, one as White (Australian and British), and one as British Indian.

The intention was to recruit 20 participants and time frames were planned to allow for data collection. There were difficulties with missed interviews and there being a limited time for further recruitment meaning that not all spaces were able to be filled. Additionally, one participant posed data integrity issues three times. Therefore, these data sets were not included and again, time constraints meant that the spaces were not able to be filled.

Data collection

Data was collected through two online interviews with each participant. A Doodle Poll was created and shared with participants which offered the lead researchers availability for interview and allowed for participants to book a preferred time and date for the first interview. Interview two was booked with each participant at the end of the first interview. Each interview was a maximum of one hour and a half.

In the first interview, consent (Appendix F) was sought and recorded, and the assessment tool was completed. Cognitive interviewing verbal probes were used to explore the domains, some items of the assessment tool and the assessment tool as a whole. The verbal probes were scripted as recommended by the autistic advisor, to remain consistent across interviews (Appendix G). The verbal probes were created in consultation with a researcher at the University of Sheffield who has experience of

cognitive interviewing. With regards to individual item exploration, it was deemed unrealistic and inappropriate given the length of the assessment tool to probe after each item. Instead, through consultation with the autistic and cognitive interview advisors, it was concluded that it was most appropriate to use verbal probes after each domain and after items in which it was deemed important to ensure that they were being understood as intended, for example, when meaning could be ambiguous. It is acknowledged that this was not possible for all items of this nature due to time constraints. Participants were encouraged to inform the researcher if any items were ambiguous and verbal probes were used. Think aloud techniques were not used due to the autistic advisor highlighting that this could be overwhelming for autistic people.

The second interview involved the completion of the acceptability (Appendix H) and usability (Appendix I) measures. Some participants needed time in the second interview to complete the assessment tool. All participants completed the full data collection within two, hour and a half interviews. Except for one participant who found the assessment tool difficult and did not wish to complete it. They still wished for their data to be included up to that point.

Interviews were held online using Google Meets between May and September 2024. Online interviews were recommended by the autistic advisors. The researcher shared their screen for the participant to see the measures. The cognitive interview was recorded and transcribed by Google Meets. The transcripts were immediately checked for accuracy and to remove any identifiable information by the lead researcher. The completion of the other measures was not recorded. A data management plan was completed and shared when obtaining ethical approval to ensure that data was being managed appropriately.

Participants provided half a day of their time to take part in this research. They were given a £75 Love2Shop voucher as compensation for their time. This was funded by ShARL for projects exploring the ICF core sets for autism.

Measures

The assessment tool consists of 257 individual items rated on a 10-point Likert scale. For most items this was rated from ‘no extent’ to ‘a great extent,’ which reflects areas of strength, typical performance or requiring support. For some items, the scale was rated from ‘hyposensitive’ to ‘hypersensitive’ and from ‘complicate/hinder’ to ‘help/improve’.

Acceptability was explored using the Theoretical Framework of Acceptability (TFA; Sekhon et al., 2022). The TFA is a 10-item measure which covers seven constructs, namely: affective attitude, burden, ethicality, intervention coherence, opportunity cost, perceived effectiveness and self-efficacy, which represent different dimensions of acceptability for healthcare interventions. The TFA uses a 5-point Likert scale.

Usability was explored using the System Usability Scale (SUS; Brooke, 1996). The SUS is a 10-item measure using a 5-point Likert scale from ‘strongly disagree’ to ‘strongly agree’. The creators of the scale describe that usability is considered ‘excellent’ when the total score lies is above 85.5, ‘good’ when the score is between 71.4 and 85.5, ‘okay’ if between 50.9 and 71.4, ‘poor’ if between 35.7 and 50.9 and ‘awful’ if below 35.7. The SUS has adequate reliability with a Cronbach’s alpha of .91 (Bangor et al., 2009). These measures were selected to remain consistent with wider research exploring the assessment tool, so that scores could be compared with other populations.

Analysis

Qualitative analysis

RTA was used to analyse the cognitive interview data. This is supported by Meadows (2021) who describe that thematic analysis allows for a full exploration of the function of the items from the participants understanding, which supports in establishing if the items provide the necessary information. That is, the validity of the assessment tool.

Once transcribing was complete, the interview data was analysed using RTA by the lead researcher. RTA is a method used to identify, analyse and report themes in data (Braun and Clarke, 2019). A theme can be defined as something important in relation to the research aims, which reflect patterns of meaning or of responses within the data. Inductive thematic analysis is data driven. Themes are drawn directly from, and therefore strongly link to, the data. They are not derived from theory. This was important because if the data was to be fit into current theoretical preconceptions, inevitably important information would have been missed. Older autistic people are underrepresented in research and so their perspectives have not been used to inform the prominent conceptualisations of autism and functioning.

RTA was conducted following Braun and Clarke's (2006 & 2019) six step method using Nvivo14 (Lumivero, 2023) software. First, the interview transcripts were read and reread to ensure familiarity with the data. Second, initial codes were created. Third, the codes were collated into potential themes. Fourth, the themes were reviewed in relation to the coded extracts. Fifth, the themes were defined. The sixth step is the write up of the analysis which can be found in the results section.

RTA was used on the data gathered for each probe that followed an item, any comments made throughout the cognitive interview and answers to the final probe

‘How would you improve this assessment so that it more accurately captures your experiences?’.

Epistemology

This research is from a realist, rather than a constructionist epistemological standpoint, because the research sought to understand meaning and experience to report the realities of the participants. Compared to exploring how their realities have been constructed. This was because the research was to explore the validity of the assessment tool, rather than to understand why participants realities are understood in a given way.

Within RTA it is emphasised that themes do not passively ‘emerge’ from the data but are actively identified by, and therefore are inevitably influenced by, the researcher (Braun and Clarke, 2019). This highlights the importance of reflexivity to understand how their views and preconceptions may influence their interpretation of the data. See Appendix J for a reflexivity statement.

Quantitative analysis

Regarding the TFA, a total score is not calculated. Instead, scores for each item for each participant are recorded and the frequency of scores for each item are used to explore the constructs individually. Overall acceptability is established from the final question ‘How acceptable was the platform to you?’ and as such the mean and standard deviation of the scores for this question are presented.

For the SUS, total scores are calculated by converting the scale responses to numbers (e.g., 1 = strongly disagree and 5 = strongly agree). For odd numbered questions, 1 is subtracted from each item score. For even numbered questions, 5 is subtracted from each item score. These scores are then summed and multiplied by 2.5 to provide the total score. Scores can range from 1-100. Through the function

tools on Microsoft Excel, the mean and standard deviation of the total scores were than established and a frequency graph of total scores was developed. These will be considered in relation to the qualitative analyses and other research which has explored the assessment tool with other populations.

Quality

The Standards of Reporting Qualitative Research (SRQR; O'Brien et al., 2014) is a 21-item measure used to consider the quality of qualitative research. It was developed from existing guidelines, reporting standards and critical appraisal criteria for qualitative research. While the SRQR is used for quality appraisal of existing research, it also provides researchers with a tool to ensure that research is conducted to a high standard from the outset. See Appendix K for the considerations of the SRQR.

Results

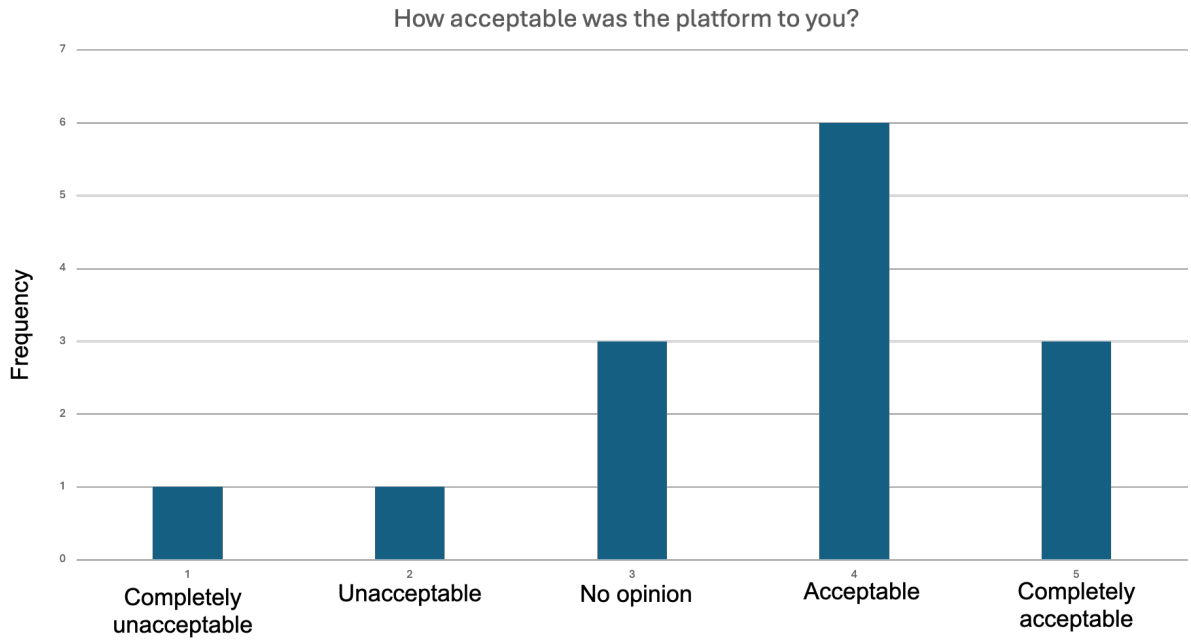
Quantitative

Acceptability

To explore whether the assessment tool was acceptable the TFA item 10 ‘How acceptable was the platform to you?’ scores were used. The assessment tool was rated negatively by two participants (completely unacceptable n=1; unacceptable n=1), neutrally by three (no opinion n=3) and positively by ten (acceptable n=6; completely acceptable n=3). See Figure 1 for a visual representation of these results. Overall, the assessment tool was found to be ‘acceptable’ (*mean*=3.64; *SD*=1.15). (See Appendix L for full TFA results).

Figure 1

Frequency of TFA item 10 scores



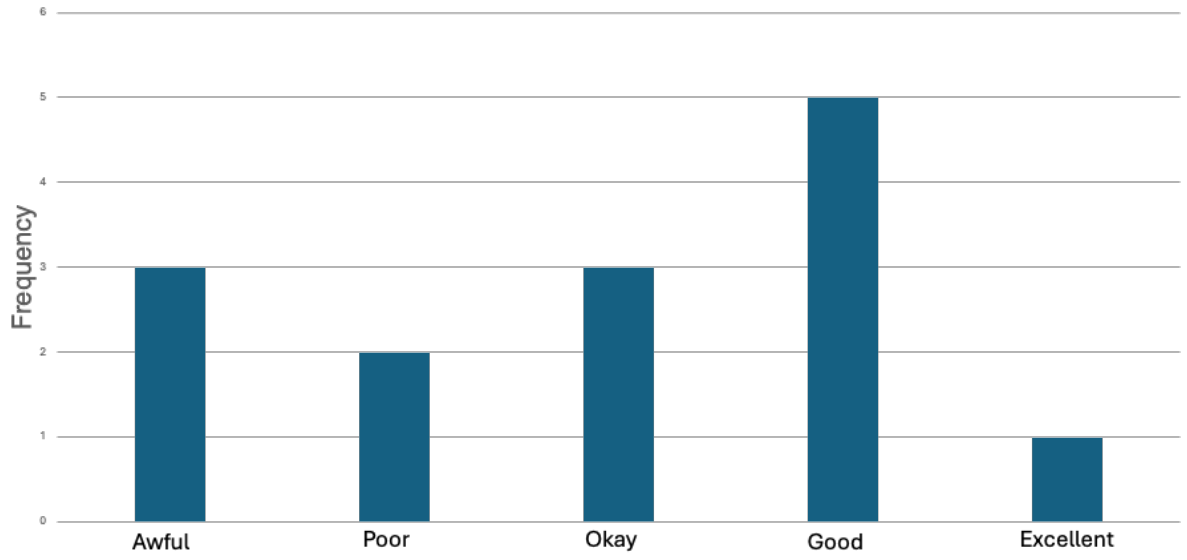
Usability

To explore the usability of the assessment tool the total SUS scores were considered. The usability of the scale was rated positively by 9 participants (excellent

n=1, good n=5, okay n=3). The remaining participants rated the usability of the assessment tool negatively (poor n=2, awful n=3). Overall, the usability of the assessment tool was found to be 'okay' (*mean*=63.79; *SD*=24.56; *range*=15-95). See Figure 2 for SUS total score frequency chart.

Figure 2

Frequency of SUS Total Scores



Reflexive thematic analysis

Five themes were developed; issues with ambiguity, an assumption of 'normal/appropriate', cultural differences, how do I boil that down into a number? and the real me vs. my masked self.

***Issues with ambiguity*.**

Participants described that several items were ambiguous. It was difficult for the participants to answer these items because they did not know how to interpret the item. One example was described by participant 1:

P1: Probably a nine. As long as you're not talking about interpreting language, as long as you're not talking about interpreting vocal tones and things like that. It's a nine.

R: How would you understand that one then to give it a nine?

P1: When I hear sounds, I hear them very quickly. I hear things other people don't hear I can tell you what direction they're coming from and usually what's making the noise.

Here, they described that from a social perspective (e.g., interpreting language) they would rate the item lower than if the question was referring to sound recognition. The ambiguity lies in whether the item is exploring sound recognition or interpreting language. For items such as this, participants described how they could be interpreted in entirely different ways, garnering entirely different responses, which may or may not be in line with the concept intending to be explored.

For others the ambiguity was around whether they should answer the questions based on what they can do, versus what they actually do. Participants made the distinction between being able to do something but not doing it. They described rating something highly because they can do it, yet finding it incredibly difficult and avoiding it, which the assessment tool failed to capture. As a result, the assessment tool may suggest that an individual is more able than they feel they are, because they physically can do something but avoid it. This is an important distinction to make given that if something is rated highly, it suggests that it is not a support need. For example:

P1: If you talk about can? An eight or nine. Yeah. Do I do it? No.

For ambiguous items, where it was unclear which perspective the item was coming from, it means that participants may have been interpreting items differently

than what was intended. As such, the assessment tool may not be capturing the intended concept. Further, it was difficult for participants to consolidate two or more interpretations into one answer, instead, they chose one interpretation to rate. This means that participants may have been rating items differently, depending on how they interpreted the item. As such, different concepts may have been rated by different participants.

An assumption of a 'normal/appropriate'.

Participants described that they understood the assessment tool to assume that there was a 'normal/appropriate' way to be. This was in relation to the scale which is coloured to denote the rating numbers as challenges, average or strengths. Some participants struggled to answer items because they did not know what was normal/appropriate as defined by others, to then rate themselves in relation to that. They were only aware of their own 'normal'. For example:

> *P1: One of the things I have trouble with is when people ask me to compare myself to normal because I have no idea what normal is. How do I know?*

Participant 9 reflected below that sometimes the assessment tool framed things as inappropriate if rated highly (e.g., thinking too fast), but they acknowledged that things can be efficient and appropriate for them, even if not to others. They described how thinking fast was helpful for them in certain situations:

> *P9: I think really fast. I can't really say that's not appropriate, but I think fast, I know what people are going to say, and I can read a bit, and I get the gist of things before I've completed the thing. But whether that's appropriate, it doesn't suit all the conversations I have. So, I don't know.*

For this participant it was an acknowledgement that that was how they were, a fast thinker, whether that was appropriate or not, which again appeared to sit

externally (i.e., what do others think is appropriate), which the assessment tool struggled to capture. In this way, their rating may have suggested a support need, when in reality thinking fast was a benefit to them in many situations. Some called for the wording to be changed by replacing normal/appropriate with sufficient to represent that something can be sufficient for what someone needs to do in a given situation, whether or not that is appropriate to others. This could call into question the relevance of the concept of appropriateness in this context, where appropriate is aligned with societal expectation. When what is appropriate for someone in each situation differs depending on the context and the task.

An issue here is that some participants rated themselves in comparison to their understanding of 'normal/appropriate', whereas others rated based on their own 'normal'. Some struggled to answer at all because they did not feel able to rate themselves compared to 'normal' when they did not know what this was. In this way, participants were answering differently depending on how they understood the scale.

Cultural Differences.

One participant shared their difficulties with the assessment tool due to issues with cultural sensitivity. In relation to the questions about 'repetitive/stereotypic movements', they shared that the behaviours used as examples reflect behaviours expected of different cultural groups. In this way, the assessment tool may not be valid for different cultural groups where these behaviours are considered typical.

> *P10: These are very limited to me, I think. To me these feel a bit like it might be mannerisms that you're expecting certain kind of cultural groups … but they were very different in the black community. We'll be stereotypical*.

They also considered that the assessment tool might not capture the behaviours which, in their example, Black boys may display. Therefore, the

assessment tool may be limited in accurately capturing the experiences of Black autistic people.

> *P10: I think what's every time we're talking about, we're talking about, you're right autistic boys your black boys, I mean, they're doing very different things. It relates into cultural sort of references.*

They also shared some language which they found particularly difficult as a Black woman.

> *P10: For me as a Black woman because I think there's the other are those and just words things like superior again. This is really difficult language if you're from minoritised groups. So again, that I did that there's a kind of superior being or person that's superior to you, that means I feel very uncomfortable.*

How do I boil that down into one number?

Participants shared difficulties around reducing their whole experience into a single number. Participants found it difficult to rate their entire experience when this differed greatly between contexts. For some, different environments impacted their functioning:

> *P3: It's either end of the scale and if I'm in a challenging environment, I think too slow, and I can't keep up with the conversation because I'm trying to process too much. But again, if the environment is right I can think very quickly.*

For some their answer depended on their interest level:

> *P1: It depends entirely on whether it's something I'm interested in or not, if I'm not interested, I don't remember, if I'm interested, I could quote it to you in 10 years' time. Word for word.*

For others their answer depended on the emotional context:

P4: It's so variable. whatever I answered, the question would need to be divided into two parts, express the emotion in a calm environment and express the emotion in an anxiety driven environment because the two answers would be very different.

For most participants that raised these issues, these were not small differences in functioning. Instead, their abilities different greatly depending on the context, highlighting how difficult it was to identify one number. Participant 9 described additional issues with this:

P9: When there's things where within one question it could be two or three different things and then you either make an average which doesn't actually capture what you feel like, or you pick one which misses the others…It seems to just make some things binary for the purposes of recording. I think you can lose the detail because you've got to just say yes, no or a bit, and it's a half hour long answer.

Here it is reflected that on items where context is a factor, detail is missed because in rating an average, this does not provide information about specific contexts. Yet, in rating one context, the other(s) are missed. The assessment tool struggles to capture the full experiences of participants in this way. In these situations, some participants picked one context to rate, while others chose to rate as an average, indicating another issue in that participants were responding to the items in different ways.

The real me versus my masked self.

Participants shared that they struggled to answer, and did not know whether to answer questions, based on the real them or their masked self. Many participants

described that how they present outwardly does not reflect how they feel on the inside. For example:

> *P15: I appear incredibly outgoing. I've done a lot of live TV and live radio and all sorts of stuff, and everyone thinks she'll do that. I am so not. I could spend days at home and not speak to anyone and so there's an impression and there's a real me. Are you asking about the real me?*

Some found it hard to consolidate their true self and their mask. Below, participant 15 shares how they can appear socially skilled but that they describe this as ‘fake’, and it is not a pleasant experience for them to mask in social situations. They chose to rate highly because they can do it through masking:

> *P15: She went but you're the most social skilled person. I know. Yeah, it's all a fake. yeah so I can completely do it. But inside I'm just screaming so put it as eight, I can fake it.*

This theme highlights potential issues in that where participants rated their masked self this does not capture their true functioning and may lead to support needs being missed. Further, the assessment tool fails to capture the nuances and longer-term impact of masking on functioning. It is unable to capture that while a person can do something by masking, there can be significant implications on their functioning due to the exhaustive nature of it. Additionally, some rated their masked self, whereas others rated their reality (i.e., not masking). In this way the assessment tool is capturing different things for different participants.

Discussion

Overall, the assessment tool was rated as acceptable and usable. This is somewhat in contrast with the qualitative feedback which highlighted various limitations. An explanation for this could be that the acceptability and usability scales do not explore concepts which the themes relate to.

The RTA highlighted potential limitations to the construct and response process validity of the assessment tool. Regarding construct validity, participants described issues with ambiguity, which can lead to differential interpretation of items. As such, they may not be measuring the intended concept (Creswell and Creswell, 2018). Ultimately, where participants were unsure of an item and understood it differently, there is the potential that their answers reflect different concepts that do not align with the intended construct. Participants described an ‘an assumption of normal/appropriate’ which also threatens construct validity. The issues here reflect that if participants were responding based on normality/appropriateness, the items were not measuring their functioning, but their understanding of and ability to conform to social normals. This threatens construct validity because for these participants, the intended construct of functioning is not being directly explored (Messick, 1995). Similarly, some participants were unsure whether to rate their true or masked self. For participants who chose to rate their masked self, their responses may reflect their social performance ability rather than measuring true functioning.

Further, participants described difficulties in rating individual items when their answer would vary based on contextual factors. The issue here is that these items appear to assume that functioning is stable, when functioning in autism is understood to be variable and context dependent (WHO, 2001, Barton et al., 2015, Lord et al., 2012). For these items, a single response did not accurately capture their

experiences. It could be argued that in this way the assessment tool oversimplified the construct of functioning. The threat to validity reflects that the tool fails to capture functioning across contexts. There is a mismatch between the construct of functioning (i.e., fluctuating and context dependent) and the tool only allowing for a single response, threatening construct validity.

Finally, participants felt that the assessment was limited in its ability to capture different cultural perspectives. For example, it was described that the behaviours which are considered ‘appropriate’ or ‘normal’ differ between cultures and that some of those described in the items may pathologise certain behaviours which are ‘normal’ in some cultures. This raises a potential concern around construct validity as the items may not accurately measure functioning across cultures (American Educational Research Association, APA, & NCME, 2014).

Response process validity is described as the extent to which the strategy a participant uses to answer an item matches the concept that the assessment intends to measure (Yuhas and BrckaLorenz, 2018). For items where there were different answers depending on context, participants were unsure if they should pick one context to rate or to rate an average of their experiences, with some using one strategy and others using the other. Similarly, where participants were unsure whether to rate their true or masked self, there was variation in how participants chose to respond. These both indicate variability in the response strategies the participants used which may suggest limitations in response process validity (Kane, 2013 & Tourangeau et al., 2000).

There is limited qualitative research exploring the validity of other tools which assess functioning in autism, to compare the qualitative feedback in this research. From a quantitative perspective, Diken et al., (2025) described that the Autism

Behaviour Assessment Scale (Harrison and Oakland, 2015) is *“psychometrically sound”* and the Vineland-3 (Hill et al., 2017) was also reported to have adequate validity (Pepperdine et al., 2017). Although exploring functioning tools for children, Hayden-Evans et al., (2022) concluded that there is variability within validity across existing measures of functioning. They also described that, compared to the assessment tool, the existing measures focused almost entirely on activity participation and neglected to explore body functions or environmental factors, with the latter being underrepresented in the assessment tools they reviewed. This potentially indicates that tools can be quantitatively adequate but still fail to fully capture a meaningful, lived experience perspective.

The acceptability and usability findings were compared with the existing literature. Freeth et al., (2026) explored the acceptability and usability of the tool with a large sample of UK adults. In line with this research, overall, the participants rated the tool as ‘acceptable’ and ‘okay’ with regards to usability. Alehagen et al., (2025a) explored usability qualitatively and reported positive feedback. Participants reported that the tool was visually appealing, had easy navigation and clear instructions. While not using the TFA, they also reported that participants described that the tool was acceptable, again in line with this research. Extending this research, they described a positive response to the tool from professionals. This is important given that they may be the ones supporting autistic people to use the tool and their agreeability may support the introduction of the tool into autism services. Overall, this research supports the existing literature and extends it by adding that the tool is acceptable and useable for older autistic people.

Alehagen et al., (2025b) assessed the construct validity of the assessment tool through an exploration of whether it could distinguish between autistic and non-

autistic individuals. The tool was found to be effective in doing so and it was concluded that it has good construct validity. The current research builds on this by adding a qualitative narrative and exploring validity specifically with older autistic adults. The finding that there could be issues with construct validity adds nuance to Alehagen et al's., (2025b) research. In line with Alehgan et al., (2025b) the current research suggested that there were no issues raised with the tool capturing all areas of functioning, what it adds is the idea that the tool misses the contextual nature of functioning. It is acknowledged that there are text boxes which allow for users to report qualitative comments. However, the participants here were suggesting that the assessment tool would more accurately capture their experiences if context could be captured in a different way.

Alehagen et al., (2025b) explored the assessment tool using content analysis and their findings were largely similar to the current research. Participants in both studies described difficulties in rating functioning on single scale due to its varied nature. Participants also both made comments about the tool implying that there is a 'normal'. However, in contrast to the current research, those participants shared that they found it useful to know where the normal range was on the scale. Whereas participants in this research found it difficult to know what normal was from a societal perspective and therefore struggled to rate themselves in relation to that because they were only aware of their own normal.

Black et al., (2019) explored the validity of the assessment tool through using direct content analysis with autistic people from Sweden, Australia and The United States. They found a high percentage of coverage across all the countries, concluding that the tool has high content validity. Fridell et al., (2022), using similar methodologies, found similar results with slightly lower coverage percentages. This

is somewhat in line with the current research in that when asked, participants did not share additional areas of functioning which the tool had missed. The current research builds on the existing literature because cognitive interviewing provides a deeper insight into how the items of the tool are understood and, in this case, explicitly asked the participants if the tool captured their full experiences.

This research has implications for the assessment tool. First and foremost, the results suggest that it would be beneficial for the tool to be updated to allow for different contexts to be considered. It would be helpful for the assessment tool to offer space for the person to describe the different contexts and then provide a rating for them. Second, the findings suggest that some items would benefit from clarification to ensure that everyone is interpreting the items in the same way. Additionally, the issues with cultural differences suggest that future research would be beneficial to ensure that the tool is culturally sensitive. It may be beneficial for the current research to be replicated with individuals from different cultural backgrounds.

This research has real world clinical implications. The assessment tool could be used in autism services to ensure a thorough assessment of functioning and offer practical information relating to appropriately supporting autistic people. This is something that is significantly lacking currently with post diagnostic support being limited to information giving and signposting (Norris et al., 2025) which does not meet current support needs (Crowson et al., 2023). The current research is working towards this being possible by ensuring that the assessment tool is usable, acceptable and valid for use with older autistic people who may encounter services.

A potential limitation of the research relates to the usability findings. The SUS primarily explores the physical usability of a tool. However, in the current research the participants did not use the tool, they observed the lead researcher do so.

Therefore, their ratings may not reflect how they would feel had they navigated the tool themselves, rather than observing the lead researcher. Following, the usability findings may reflect perceived usability rather than actual usability. To overcome this, future research could explore the usability of the tool with older autistic adults who have completed the assessment tool themselves.

Participation for this research was online. Therefore, the sample may have been vulnerable to self-selection bias (Buchanan and Hvizdak, 2009) in that people who opt to take part may be meaningfully different and the views of those that opted out are not captured (Kraut et al., 2004). Additionally, it is not guaranteed that everyone has equal access to the internet (Kraut et al., 2004), limiting who can take part. Following, the sample may not be representative of older autistic people.

Another potential issue with online research is fraudulent participation where the same participant tries to participate multiple times (Bethlehem, 2010 & Wright, 2005). This was an issue with one participant. They did not turn their camera on so their identity could not be verified against their provided information. The researcher did not question this due to wanting to allow participants to take part in a way that was most comfortable. However, the participants voice was recognised. Their identity was questioned and did not match what they initially shared. Their data was excluded and meant that genuine participants missed out. Lawlor et al., (2021) propose a framework for online research to detect fraudulent participation. They suggest that fraud prevention needs to be considered and embedded within the study design. It is being recommended that in future research, participants are made aware that they will have to turn their camera on to verify their identity.

Conclusion

This research sought to explore the acceptability, usability and validity of the assessment tool with older autistic people. The assessment tool was found to be acceptable and usable, however, potential threats to validity were highlighted. Specifically, issues with construct and response process validity were raised. These issues reflected difficulties with ambiguity, uncertainty as to how to answer items (e.g., based on masked vs. true self), limitations within the assessment tool in capturing functioning across contexts and limitations to cultural sensitivity. Following, there is scope to further improve the assessment tool by addressing these issues. For example, through making changes to ensure that it captures the variability of functioning and by adding clarity in the introductory information regarding how to respond to items. This is important work given the current lack of post-diagnostic support for autistic people and the potential use of the assessment tool in guiding post-diagnostic support provisions. Future research would be helpful in continuing to explore acceptability, usability and validity with different populations to support its use in autism services.

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Appendices

Appendix A

Ethical Approval

Downloaded: 07/01/2025
Approved: 04/02/2024

Kate Johnstone
Registration number: 220237826
Psychology
Programme: Doctorate in Clinical Psychology

Dear Kate

PROJECT TITLE: Exploring the Validity, Acceptability and Usability of the International Classification of Functioning, Disability and Health (ICF) Core Sets Assessment Tool for Older Autistic People
APPLICATION: Reference Number 057502

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 04/02/2024 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 057502 (form submission date: 02/02/2024); (expected project end date: 31/05/2025).
- Participant information sheet 1131235 version 3 (02/02/2024).
- Participant consent form 1131453 version 2 (02/02/2024).

The following amendments to this application have been approved:

- Amendment approved: 05/07/2024

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Admin
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Admin (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Participant Debrief

Thank you for taking part in my study. The aims of the study were to explore a post-diagnostic support tool with autistic people who are 50 years old. The hope is that this can be used to improve post diagnostic support for autistic people.

The assessment tool we went through asked questions about different aspects of your life, some of which may have been difficult for you to think and talk about. I hope that this did not cause you distress. If this did cause any distress, please see below resources for support:

- Shout is a free service which is access via text on 85258
- Samaritans can be called on 116 123 or emailed on jo@samaritans.org and offer a space to talk freely and to be listened to without judgement
- Sheffield Support Hub within Mental Health Matters can be accessed using 07890 987 384 for free mental health support which is tailored to your preferences
- Adult Autism Support Hub within Mental Health Matters can be accessed using 07811 589 909. They offer a range of services including mental health advice, peer support and workshops.

You will receive your voucher via email or in the format which we agreed for it to be shared with you.

I would also like to remind you that you still have the right to withdraw your information from this study. Please let lead researcher, Kate Johnstone, know if you wish to withdraw

using kjohnstone1@sheffield.ac.uk. You are able to withdraw your information for three weeks after your final interview. After this date the information will be used in analysis. I also wish to remind you that you will not be identifiable in the research.

Thank you again for taking part in this research.

Appendix C

Study Advert

Do you have a diagnosis of autism? Are you over 50 years of age?

I am looking for participants for a research study aimed to exploring a post-diagnostic support tool for autistic people who are over 50 years old

We hope that the research will work to improve post diagnostic support for autistic people

I am a Trainee Clinical Psychologist and this project will form part of my thesis. You will be eligible to take part if you:

- Have a formal diagnosis on the autism spectrum (e.g., autism, Asperger Syndrome, autism spectrum disorder/condition)
- Are fluent in English
- Do not also have a learning disability
- Are over 50 years of age

If you are interested in taking part, please contact the lead researcher, Kate Johnstone, at kjohnstone1@sheffield.ac.uk.

Appendix D

Participant Information Sheet

INFORMATION SHEET

(Ethical clearance number: *057502)*

You are being invited to take part in a research project being conducted by Kate Johnstone. Before you decide, it is important to understand why the research is being done and what it will involve. Please read the following information carefully.

Why have I been invited?

You have been invited to take part in this research project because you are over 50 years of age and have a formal diagnosis on the autism spectrum (e.g., autism, Asperger Syndrome, autism spectrum disorder/condition) and received the diagnosis from a healthcare professional in the UK.

What is the aim of the study?

This study is exploring an assessment designed for autistic adults that helps to identify strengths and areas of support. I am looking to explore the tool with autistic people who are 50 years old and above to see if the assessment is exploring relevant areas, that it is acceptable and that it is user-friendly for this group of people.

What will happen if I take part?

At the end of this information sheet you will be asked to complete a screening questionnaire. You will be contacted via telephone or email (you will be asked to indicate your preferences as part of the screening questionnaire) by the lead researcher within a week of completing it to let you know if you have been selected to participate. If you are selected, you will be asked to take part in two interviews, each will be an hour and a half interview. In the first interview, you will go through a post diagnostic assessment tool and be asked for your feedback on the tool. The tool will ask you questions about your day-to-day life and at the end will give you a profile which explains your strengths and things that you find more difficult, as well as what

things in your environment that are seen as helpful or less helpful. In the second session, you will be asked to complete two questionnaires about the tool. All of the information will be anonymous.

The interview will take place online via Google Meets. If you are selected to take part, we can discuss if there is anything you need to make participating more accessible. You are welcome to invite someone to support you if this would be helpful. For example, a friend or relative. However, they are unable to participate during the interview. This person is not allowed to speak for you but can be there for support.

Do I have to take part?

No, it is up to you whether you would like to take part. Participation in this study is voluntary. If you decide to take part, you can keep this information sheet and will be asked to sign a consent form after having the chance to ask any questions at the first interview. You can withdraw without giving a reason, three weeks after your final interview. After this date the data will be included in the report. I want to remind you again that the information will anonymous.

What are the benefits of taking part?

You have the opportunity to partake in a post diagnostic assessment and the results, which explain your strengths, challenges and what in your environment is helpful and less helpful, are yours to be able to keep and use. This is something we hope will be helpful for you, and might be able to help others support you too. A written report of the findings will be published and we hope that this will be helpful in bettering the post diagnostic support for people after receiving a diagnosis of autism.

Will I be financially compensated for my time?

You will receive a £75 voucher via email upon completing the study. You will only receive the voucher if you take part in both interviews. Following the second interview, the voucher will be emailed to you. If you prefer, we can think about other ways for the voucher to be shared with you.

What if there is a problem?

If you feel that there is a problem at any time, you can let the researcher know. This may be a topic that is difficult to talk about or could feel distressing. If you experience any distress during the interviews, the researcher will be able to discuss this with you and discuss what further support might be of help (e.g. contacting your GP). The researcher may stop the interviews if they feel that you are becoming distressed. The following are additional places where you can access support:

- Shout is a free service which is access via text on 85258
- Samaritans can be called on 116 123 or emailed on jo@samaritans.org and offer a space to talk freely and to be listened to without judgement
- Sheffield Support Hub within Mental Health Matters can be accessed using 07890 987 384 for free mental health support which is tailored to your preferences
- Adult Autism Support Hub within Mental Health Matters can be accessed using 07811 589 909. They offer a range of services including mental health advice, peer support and workshops.

What will happen with my information?

The first interview will be audio recorded and will be transcribed using an approved University of Sheffield transcriber, or by the lead researcher. There will be no identifiable information (e.g., your name) in the interview transcripts. Following this it will be analysed using thematic analysis. The data collected in the second interview through the two measures will be saved in a secure file. Your information will be stored in a secure file which only the lead research (myself) and the research supervisor (Professor Megan Freeth) are able to access. This information stored will not be identifiable.

Will all the information be kept confidential?

All the information we collect about you will be kept strictly confidential. You will not be identifiable in any reports or publications.

The only exception to this would be if during the interview the researcher became concerned about a risk of harm to yourself (e.g. suicidal risk), or someone (e.g. a child or another adult) you talk about (e.g. risk of neglect or physical harm). In such a situation the researcher would discuss the need to breach confidentiality with you; the aim of this would always be in order to support yourself and those you mention and ensure safety (for example, it may involve letting relevant services know about the situation in order to help provide those involved with support).

What if I wish to complain about the way the study has been carried out?

In the first instance you can contact the lead researcher, Kate Johnstone on kjohnstone1@sheffield.ac.uk. Alternatively, you can contact the collaborator involved in the project; Megan Freeth, Lecturer and Researcher on m.freeth@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact Dr Chris Martin, Head of Department on psy-hod@sheffield.ac.uk**.**

Has this project undergone ethical review?

Yes. This project has received ethical approval from the University of Sheffield's Psychology Ethics committee.

What will happen to the results of the study?

The results will be submitted as part of the researcher's doctoral thesis in May 2025, then prepared for publication in 2025. You can let the researcher know at the start of the study if you would like a copy of this and this can be sent to you.

The University of Sheffield is organising and funding this research. This project has been ethically approved via the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure.

Contact Information

This research is being conducted by **Kate Johnstone,** Trainee Clinical Psychologist. This research will be used to write a thesis which fulfils part of their doctoral training. If you have any questions about the research, you can use kjohnstone1@sheffield.ac.uk to ask any questions.

Additional Information about your data

New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health, we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

What happens next?

If after reading the above information, you wish to proceed, please click the link below to complete the screening questionnaire to ensure you are eligible to take part in the study.

Please ensure to provide your contact details when asked as the link is anonymous and this ensures you can be contacted. By clicking the link, you are consenting to complete the screening questionnaire. This does not mean that you consent to take part in the whole study. If part way through the screening survey you wish to withdraw consent, please close your browser.

https://shef.qualtrics.com/jfe/form/SV_6rH3Rvo0rnis4Ki

Thank you for reading this information sheet and for considering taking part in this research.

Appendix E

Screening Survey

- Do you have a diagnosis of autism (or variants e.g., Asperger's), as diagnosed by a healthcare professional in the UK? Yes No

[text box allowing for further information to be provided]

- Are you over 50 years of age? Yes No

- How do you identify your gender? Male, Female, Non-binary, Other, Prefer not to say

[text box allowing for further information to be provided]

- Please describe your ethnicity. E.g., White British, Asian, Indian

[text box allowing for description]

- How do you want to be contacted about taking part in the study? Email, Phone

Please provide contact details below

[text box]

Appendix F

Consent Form

Consent Form

Exploring the validity, acceptability and usability of the ICF Core Sets for Autism assessment tool in under-represented groups.

Please tick the appropriate boxes

[redacted] Switch account

Not shared

Taking Part in the Project

I have read and understood the project information sheet or the project has been fully explained to me. (If you answer 'No' to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)

- [ ] Yes
- [ ] No

I have been given the opportunity to ask questions about the project.

- [ ] Yes
- [ ] No

I agree to take part in the project. I understand that taking part in the project will include two, hour and a half interviews. In the first interview I will go through assessment tool and be asked for my feedback. In the second interview I will complete two questionnaires about the assessment tool.

- [ ] Yes
- [ ] No

I understand that the first interview will be recorded via Google Meets. You will be told when the recording starts and stops.

- [ ] Yes
- [ ] No

I understand that my taking part is voluntary and that I can withdraw from the study anytime up to three weeks after my final interview. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.

- [ ] Yes
- [ ] No

How my information will be used during and after the project .

I understand my personal details such as name, phone number and email address etc. will not be revealed to people outside the project.

- [ ] Yes
- [ ] No

I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.

- [ ] Yes
- [ ] No

I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.

- [ ] Yes
- [ ] No

I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

- [ ] Yes
- [ ] No

I give permission for my contact details (name and email address) to be added to Sheffield Autism Research Lab's database for potential future participants. I understand that if I say yes, I may be contacted to participant in future research. This does not mean that I am obliged to agree to take part, just that it will be offered. This will not impact my participation in this study.

- [ ] Yes
- [ ] No

So that the information you provide can be used legally by the researchers

I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.

- [ ] Yes
- [ ] No

Consent

Name of participant:

Your answer

Date:

Date

dd/mm/yyyy

I give my consent to participate in the research.

- ◯ I consent
- ◯ I do not consent

Project contact details for further information:
Lead researcher: Kate
Johnstone kjohnstone1@sheffield.ac.uk

Research supervisor: Dr Megan Freeth m.freeth@sheffield.ac.uk.

In the event of a complaint if you feel able, please contact the lead researcher or research supervisor. Alternatively, please contact:
Dr Chris Martin,
Head of Department, Department of Psychology: psy-hod@sheffield.ac.uk

Department of Psychology

G07

Interdisciplinary Centre of the Social Sciences (ICOSS)

219 Portobello

Sheffield

S1 4DP

Submit

Clear form

Appendix G

Cognitive Interview Script

"Now we will go through the assessment tool. As we go through the items, I will ask you some questions about them. I might ask you to explain what different words mean to you, and I might ask you to rephrase an item in your own words. If there are any items that you don't understand, I encourage you to let me know so that we can think about how to make these items clearer."

Questions for if it is raised that a question has not been understood: What makes this item hard to understand? How could this item be made clearer?

After introduction: Is it clear what the assessment will do? Could anything make the introduction clearer?

Body Functions

Domain descriptor: What does the term 'body function' mean to you? Is there anything that could be made clearer?

Time frame question: Is it clear how you should answer the questions?

Sleep (5 questions)

Energy and drive (5 questions)

6) What does the term 'sufficient level of energy' mean to you?

7) What does the term 'motivation and drive' mean to you?

9) What does the term 'impulses' mean to you?

10) Can you repeat this item in your own words?

Perception (5 questions)

What does the term ‘perception’ mean to you?

Emotions (3 questions)

16) What does the term ‘suit the situation’ mean to you?

17) What does the term ‘appropriate’ mean to you?

Memory (5 questions) and General orientation (3 questions)

Attention (3 questions)

28) Can you repeat this item in your own words (stopped asking AT11)

Thinking (8 questions)

Language and body (4 questions) and Speech (4 questions)

Motor functions and coordination (2 questions)

46) Can you repeat this item in your own words? Changed to what does motor activity level mean to you?

Temperament/personality (7 questions)

49) What does the term ‘accommodating’ mean to you?

50) What does the term ‘conscientious’ mean to you?

51) What does the term ‘even tempered’ mean to you?

53) What does the term ‘optimistic’ mean to you?

54) What does the term ‘confident’ mean to you?

55) What does the term ‘trustworthy’ mean to you?

Behavioural style (6 questions)

56) What does the term ‘adaptable’ mean to you?

60) What does the term ‘persistent’ mean to you?

61) What does the term ‘approachable’ mean to you?

Intellectual ability (1 question)

62) How did you come to this answer?

Social ability (1 question)

63) How did you come to this answer?

Sensory processing (8 questions)

What does the term ‘hyposensitive’ mean to you?

What does the term ‘hypersensitive’ mean to you?

Involuntary/unusual movements (2 questions)

After domain: Any comments about the items in this section? How was it to try and think of the past month generally? What do you automatically think of in time frame? How well can you recall over this time?

Activities and participation

Domain descriptor: What does the terms ‘activities and participation’ mean to you? Is there anything that could be made clearer?

Time frame question: Is it clear how you should answer the questions?

Use of senses and focus (3 questions) and Learning (6 questions)

80/82) What does the term ‘enquire’ mean to you?

Performing tasks (5 questions)

85/86) What does the term ‘component’ mean to you?

87) Can you repeat this item in your own words? Don’t ask this

89) What does the term ‘adapt’ mean to you?

Applying knowledge (4 questions)

91) Can you repeat this item in your own words?

Demands and changes (7 questions)

94) Can you repeat this item in your own words?

97) Can you repeat this item in your own words?

100) What does the term ‘crisis’ mean to you?

What does the term ‘manage’ mean to you?

Receiving information (4 questions) and Giving information (1 question)

Conversations (9 questions)

Self-care (8 questions)

Health behaviours (10 questions)

129) What does the term ‘health care provider’ mean to you?

Household chores (10 questions)

Use of transport (4 questions)

Social interaction (13 questions)

147) Can you repeat this question in your own words?

148) Can you repeat this question in your own words?

151) What does the term ‘appreciation’ mean to you?

152) What does the term ‘tolerance’ mean to you?

Social relations (10 questions)

What does the phrase ‘build and maintain relationships’ mean to you?

School and high school (not relevant – 5 questions)

College university (not relevant – 4 questions)

Work (potentially relevant – 9 questions) and Economics (5 questions)

Playful activities and gaming (2 questions) and Community life (4 questions) and Empowerment (2 questions)

What does the term 'empowerment' mean to you?

195) What does the term 'social activities' mean to you?

199) What does the term 'assert' mean to you?

After domain: Any comments about the items in this section? How was it to try and think of the past month generally? How well can you recall over this time?

Environmental factors

Domain descriptor: Does it make sense? Is there anything that could be made clearer?

The attitudes of others (11 questions)

Support and relationships (9 questions)

School and education (not relevant – 3 questions)

Community services (6 questions)

What do the terms 'personal assistants', 'housing support', 'mentors' and 'carers' mean to you?

What do the terms 'administrators in support', 'service' and 'welfare systems' mean to you?

What does the term ‘society’ mean to you?

What does the term ‘subcultures’ mean to you?

Assistive products and technology (3 questions)

Diet and supplements (8 questions)

Light and sound conditions (2 questions)

Medicine (7 questions)

Communication services (5 questions)

Media (5 questions)

What does the term ‘hinder’ mean to you?

What does the term ‘complicate’ mean to you?

After domain: Any comments about the items in this section? How was it to try and think of the past month generally? How well can you recall over this time?

How would you improve this assessment so that it more accurately captures your experiences?

Appendix H

Theoretic Framework of Acceptability Scale

Table 1 Generic form of TFA acceptability questionnaire

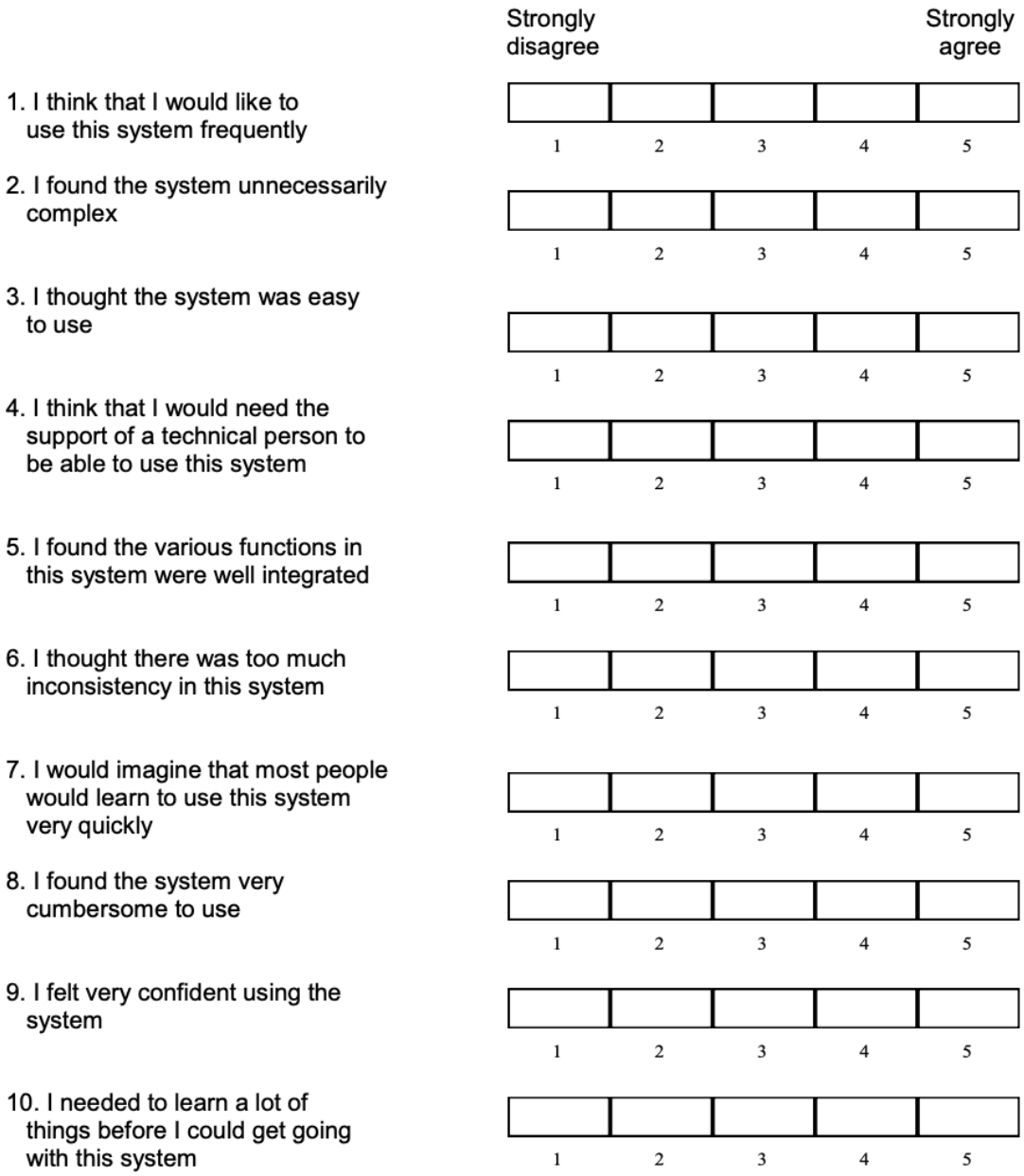
TFA Construct	Questionnaire item
Affective attitude *How an individual feels about the intervention*	**Affective attitude:** Did you like or dislike [intervention]? Strongly dislike (1) | Dislike (2) | No opinion (3) | Like (4) | Strongly like (5) ***OR*** How comfortable did you feel [behaviour *e.g. to engage with*] [intervention]? Very uncomfortable (1) | Uncomfortable (2) | No opinion (3) | Comfortable (4) | Very comfortable (5)
Burden *The amount of effort required to participate in the intervention*	How much effort did it take [behaviour *e.g. to engage with*] [intervention]? No effort at all (1) | A little effort (2) | No opinion (3) | A lot of effort (4) | Huge effort (5)
Ethicality *The extent to which the intervention has good fit with an individual's value system*	**Ethical Consequences:** There are moral or ethical consequences [behaviour *e.g. to engage with*] [intervention] Strongly disagree (1) | Disagree (2) | No opinion (3) | Agree (4) | Strongly agree (5) ***OR*** How fair is [Intervention] for [people/ participants/ recipients] with [condition]? Very unfair (1) | Unfair (2) | No opinion (3) | Fair (4) | Very fair (5)
Perceived effectiveness *The extent to which the intervention is have achieved its intended purpose*	The [intervention] has improve [behaviour/ condition/ clinical outcome]: Strongly disagree (1) | Disagree (2) | No opinion (3) | Agree (4) | Strongly agree (5)
Intervention coherence *The extent to which the participant understands how the intervention works*	It is clear to me how [intervention] will help [manage/ improve] my [behaviour/ condition/clinical outcome] Strongly disagree (1) | Disagree (2) | No opinion (3) | Agree (4) | Strongly agree (5) **Please tell us more about your views*
Self -efficacy *The participants confidence that they can perform behaviour(s) required to participate in the intervention*	**Self-efficacy:** How confident did you feel about [*behaviour e.g. engaging with*] [intervention]? Very unconfident (1) | Unconfident (2) | No opinion (3) | Confident (4) | Very confident (5)
Opportunity costs *The benefits, profits or values that were given up to engage in the intervention*	**Opportunity Costs:** [Behaviour *e.g. engaging in)* [intervention] interfered with my other priorities Strongly disagree (1) | Disagree (2) | No opinion (3) | Agree (4) | Strongly agree (5)
General Acceptability	How acceptable was the [intervention] to you? Completely unacceptable (1) | Unacceptable (2) | No opinion (3) | Acceptable (4) | Completely acceptable (5)

Note: [intervention] should be replaced with the name of the healthcare intervention (e.g. Did you like or dislike the [feedback materials]?

[Engaging with/ engaging with intervention] should be replaced with the specific behaviour participants are required to complete to engage with the intervention (e.g. how much effort did it to take you to [book your own appointment]? [clinical condition] should be replaced with the name of the clinical condition associated with the intervention (e.g. it is clear to me how [feedback reports] will result in improvements in [blood transfusion practice].

Appendix I

System Usability Scale



Appendix J

Reflexivity Statement

It is essential to acknowledge my, the researcher's, position as a white, non-autistic, 28-year-old, female. These characteristics place me in a distanced position from the participants, and it is inevitable that my lived experiences were largely different from the participants. Researcher preconceptions need to be especially considered given the more outside perspective they are coming from. I have a substantial education in psychology and years of experience working with autistic people in mental health services. This means that despite seeking to use an inductive approach, the research may be influenced by my clinical knowledge/experience and learnt theory. To mitigate this firstly, autistic advisors were sought to ensure that the research was designed from the outset considering an autistic perspective rather than purely from a neurotypical one. Further, reflections were made throughout the research. Additionally, regular research supervision was used to gain an additional perspective and to discuss anything that arose. The latter points allowed for ongoing reflection of how my position might have influenced the research. It is also acknowledged that despite this, it may still be reflected in the analysis. However, it is also considered that this is not inherently a flaw but a resource. It is acknowledged that themes were constructed through an interaction between participants shared experiences, my interpretations and theoretical perspectives.

Appendix K

SRQR Checklist

		SRQR considerations	My comments/reflections
Title and abstract	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title explicitly describes what the study aims to do and describes the methodology.
	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Abstract includes the identified elements. It briefly describes the background and rationale for the research, the methods used to conduct the research, the results and conclusions with points for practitioners
Introduction	Problem Formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	The background as to why this research needs to take place is described in detail with the rationale and other relevant empirical work is considered. This is used to rationalise the problem statement.

	Purpose or research question		The aims of the research are explicitly stated at the end of the introduction.
		Purpose of the study and specific objectives or questions	
Methods	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	The qualitative approach that's used (cognitive interviewing) was described and the rationale for using this method was also described. The standpoint of the research was also considered and described.
	Researcher characteristics and reflexivity		My characteristics were explicitly considered but due to the word count my reflexivity statement is in the appendices, so it is still available for consideration by the reader.
		Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	
	Context	Setting/site and salient contextual factors; rationale	The context of the study was described in detail, including the location, the participants, recruitment, when it happened. The rationale for this decision is also described.

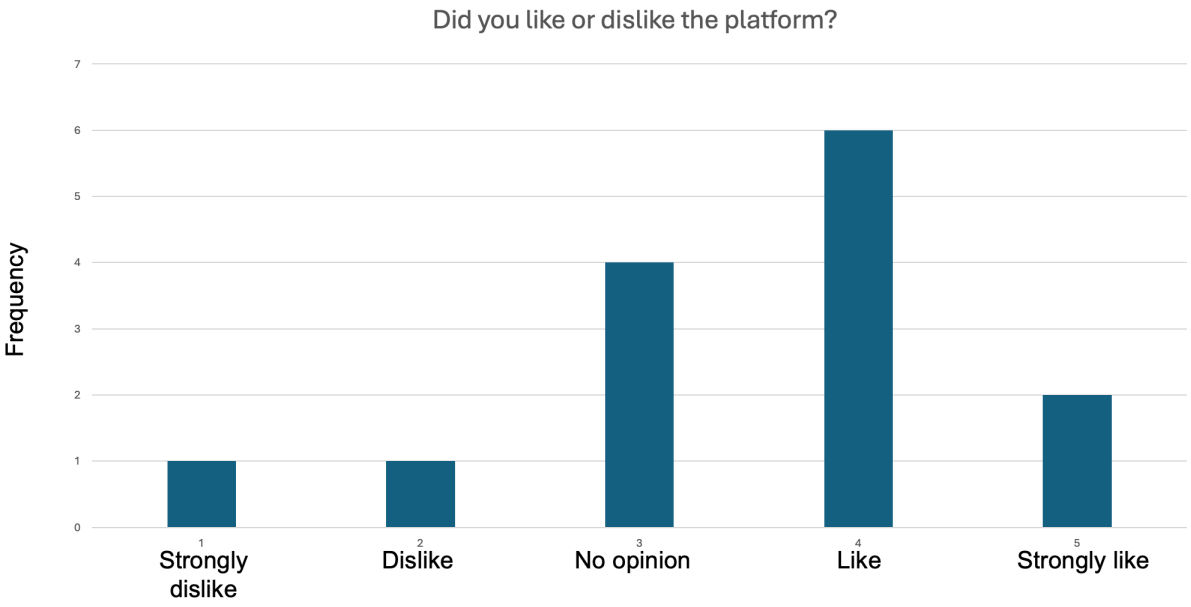
Samply strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	As described above the sampling strategy was clearly stated and rationalised.
Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Ethical approval was granted and the evidence is in the appendices.
Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	The type of data collected was described, the dates of data collection were detailed, how it was collected was also described.
Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection, if/how the instruments) changed over the course of the study	The scales were described in detail and where possible provided in the appendices. How the data was recorded was also described.
Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Relevant participant demographics were described, and how they participated was described.

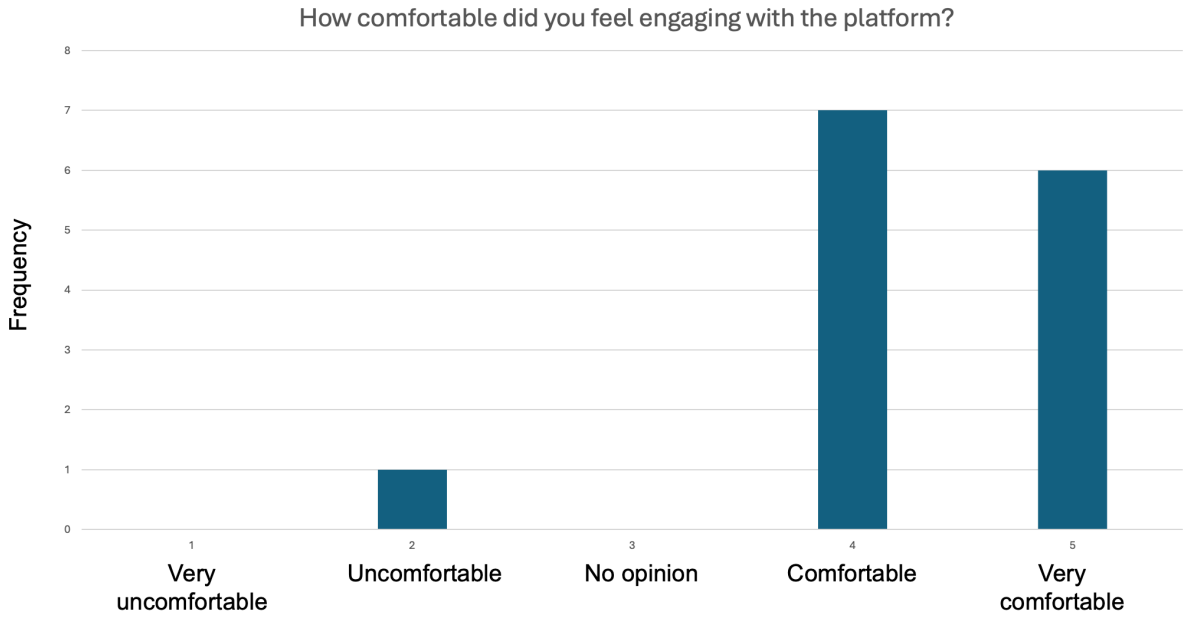
	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	The data processing was described and including that I anonymised and transcribed it, and I described that I had a data management plan that was approved by the ethics board.
	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Data analysis was described in detail in terms of the process of reaching themes, and the approach to analysis, thematic analysis, was described and rationalised.
	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Methods to enhance trustworthiness were considered and if not used e.g., two analysers, this was rationalised as it was not in line with the method of analysis.
Results/findings	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Main findings were presented in a clear way describing themes and my interpretations of the data. Integration with prior research was done in the discussion.
	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Plenty of quotes have been used to make sense of the themes and interpretations.

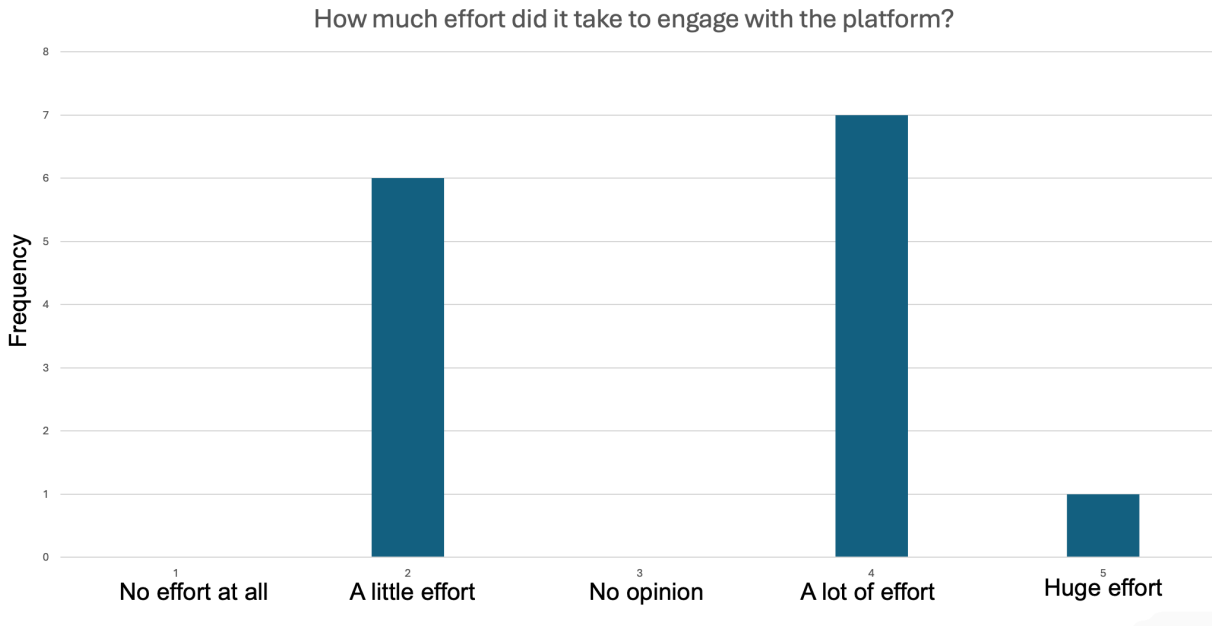
Discussion	Integration with prior work, implications, transferability, and contributions) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Findings were summarised clearly and the research findings were linked to each other, and existing literature. The implications and applications were considered and described. Future research directions were also described
	Limitations	Trustworthiness and limitations of findings	Limitations were clearly described.
Other	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were	N/A
	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and	Where funding was received this has been stated clearly where relevant.

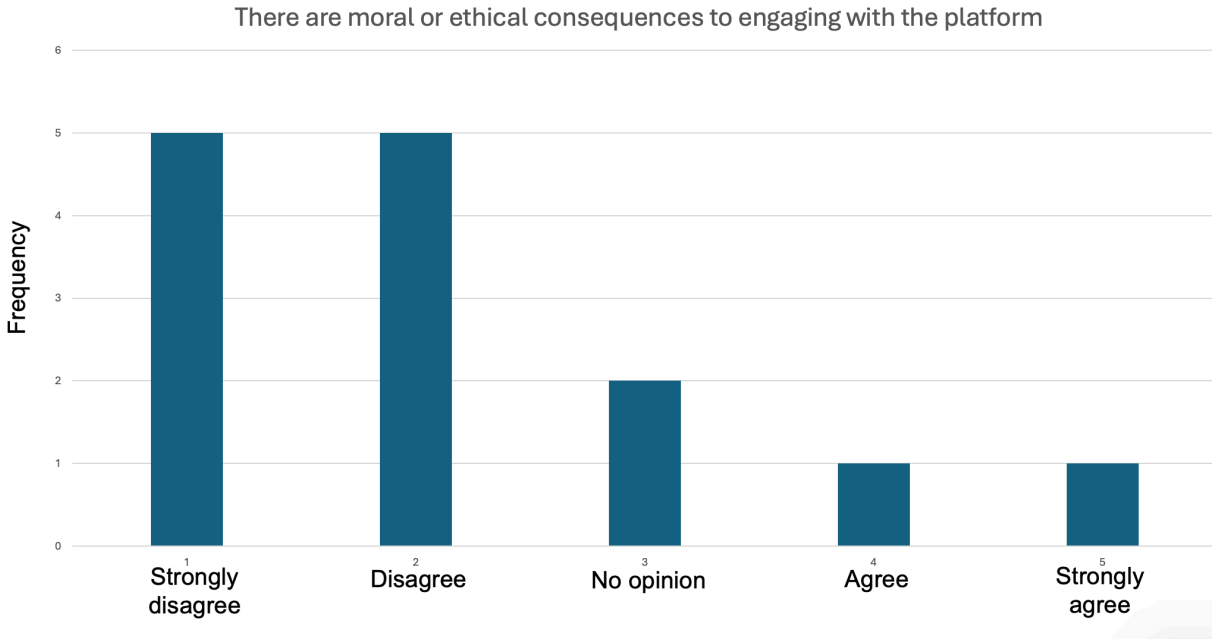
Appendix L

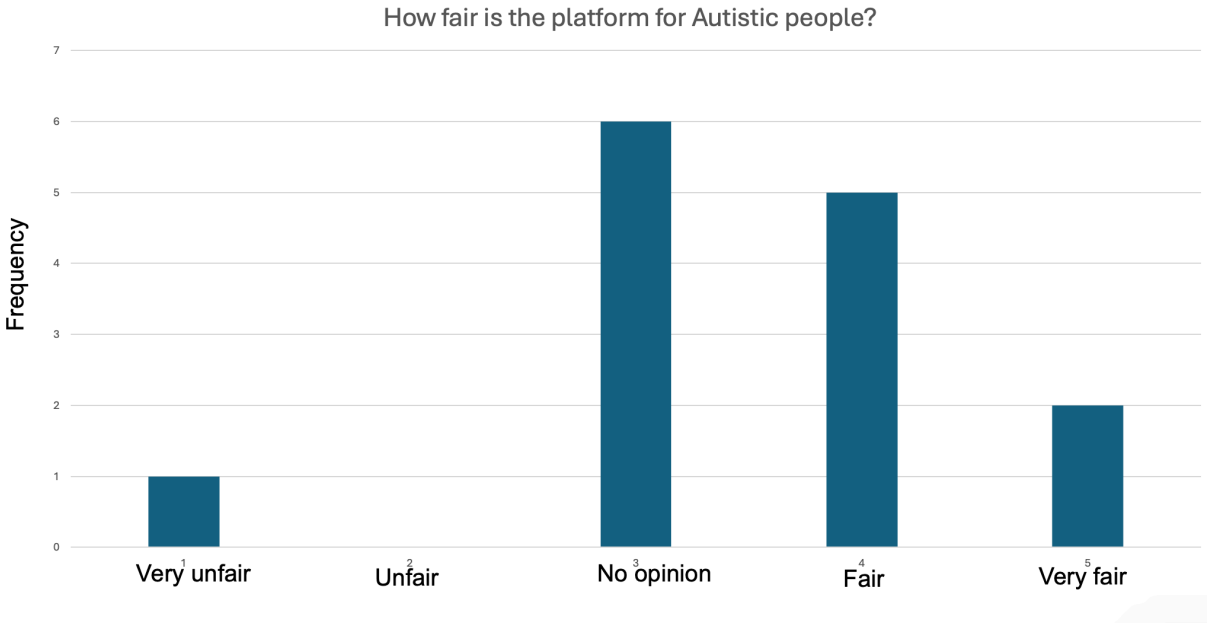
Full TFA Results

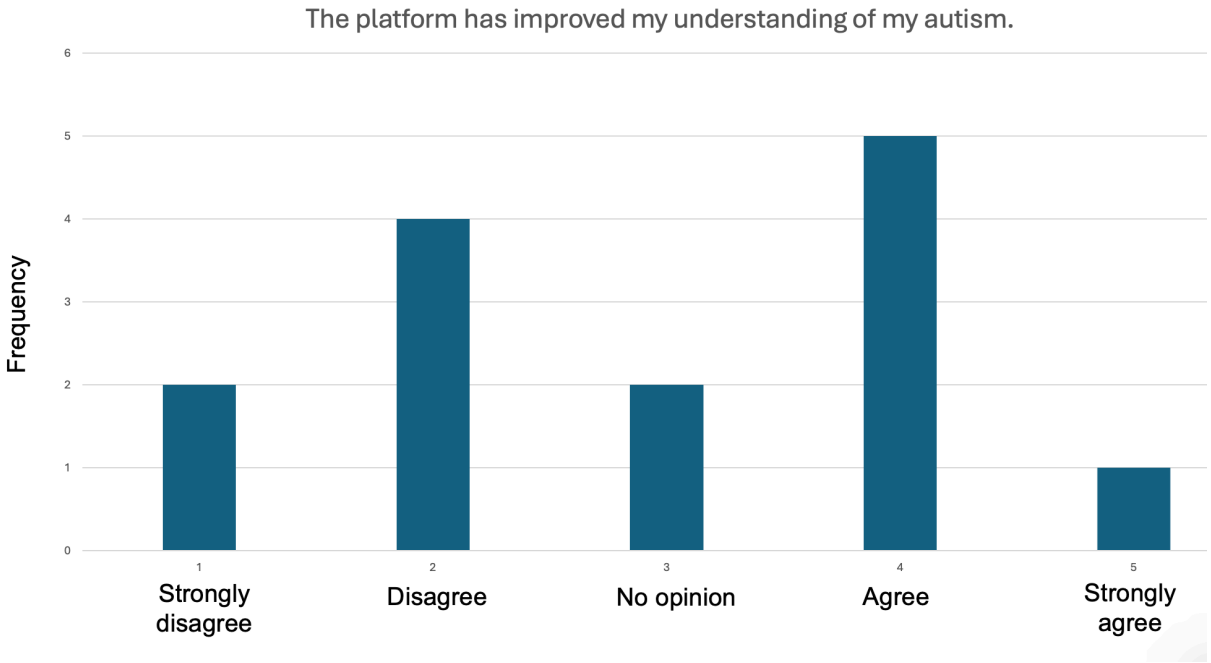


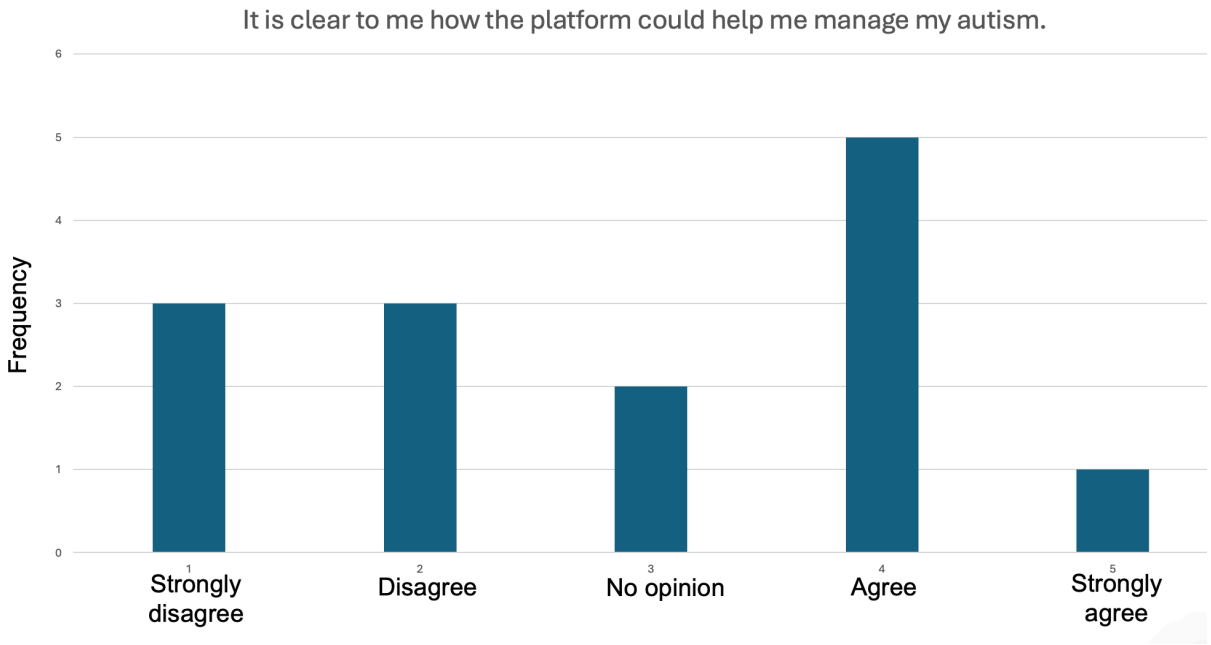


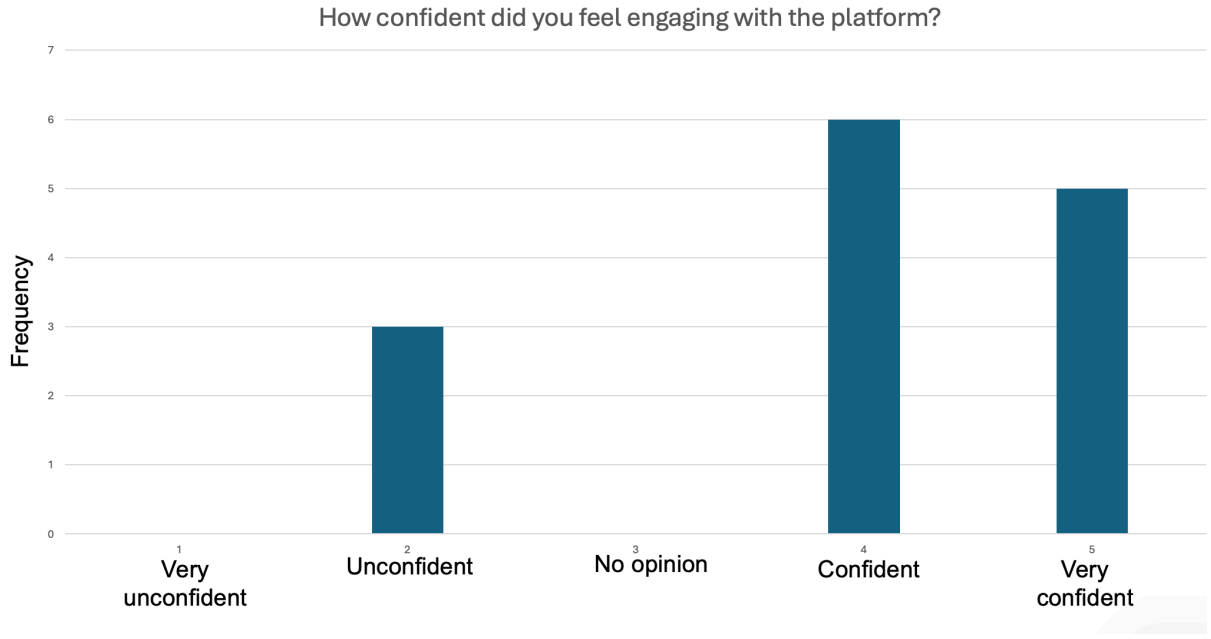

How much effort did it take to engage with the platform?
Frequency
0
1
2
3
4
5
6
7
8
1
No effort at all
2
A little effort
3
No opinion
4
A lot of effort
5
Huge effort

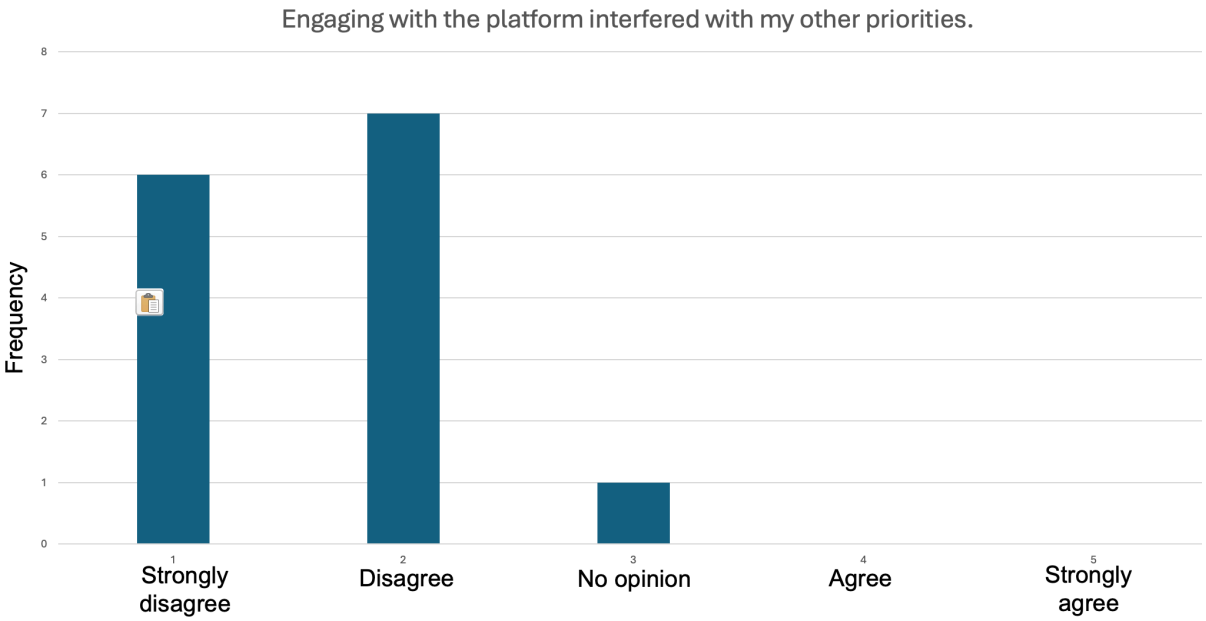

There are moral or ethical consequences to engaging with the platform
Frequency
0
1
2
3
4
5
6
1
Strongly disagree
2
Disagree
3
No opinion
4
Agree
5
Strongly agree


How fair is the platform for Autistic people?
Frequency
0
1
2
3
4
5
6
7
1
Very unfair
2
Unfair
3
No opinion
4
Fair
5
Very fair


The platform has improved my understanding of my autism.
Frequency
0
1
2
3
4
5
6
1
Strongly disagree
2
Disagree
3
No opinion
4
Agree
5
Strongly agree


It is clear to me how the platform could help me manage my autism.
Frequency
0
1
2
3
4
5
6
1
Strongly disagree
2
Disagree
3
No opinion
4
Agree
5
Strongly agree


How confident did you feel engaging with the platform?
Frequency
0
1
2
3
4
5
6
7
1
Very unconfident
2
Unconfident
3
No opinion
4
Confident
5
Very confident


Engaging with the platform interfered with my other priorities.
Frequency
8
7
6
5
4
3
2
1
0
1
Strongly disagree
2
Disagree
3
No opinion
4
Agree
5
Strongly agree