Post-diagnostic psychoeducation and autistic adult's experiences of disclosure.

A thesis submitted in partial fulfilment of the requirements for the Doctorate in Clinical Psychology

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Declaration

This thesis has been submitted for the award of Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted to any other institution, or for the purpose of obtaining any other qualifications.

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Lay Summary

Literature Review

"Psychoeducation" involves to learning and understanding one's own mental health condition and is a commonly used component in talking therapy. Some adult autism services within the UK routinely offer psychoeducation adapted for autism to support recently diagnosed autistic people to learn about autism and help them come to terms with the diagnosis. It is unknown whether autism psychoeducation for newly diagnosed adults is effective as no systematic review of the research literature has been done. The aim of this review is to find out whether autism psychoeducation designed for autistic adults without a learning disability is effective for improving autistic people's quality of life and mental health, including depression, anxiety, and self-esteem. The review also explores whether psychoeducation increases acceptance and knowledge of an autism diagnosis.

The results showed that psychoeducation on its own or when combined with another common psychological therapy, such as mindfulness-based therapies and cognitive behavioural therapy, had some positive effects for improving depression, anxiety, and quality of life in autistic adults. Only a few studies reported data for self-esteem, knowledge, and acceptance. There were no effects on self-esteem but some positive effects were shown for knowledge and acceptance. Quality appraisal of the study indicated that study designs varied across studies and sample size were insufficient in some studies. Furthermore, there is currently no standardised tools for measuring knowledge and acceptance of autism which could have increased the risk of bias for these two measures. A further methodological limitation of the studies published to date was that only a very small number of studies involved autistic people in the design and delivery of the interventions.

Empirical Project

Increasing number of people are receiving diagnosis of autism in adulthood. However, there are very few studies exploring autistic adult's experiences of "disclosure", that is, to tell others about their autism. The aim of this study is to explore autistic adults' experiences of telling other people that they are autistic after receiving their diagnosis as an adult. Twelve autistic adults were interviewed about their experiences of disclosing their diagnosis and Interpretative Phenomenological Analysis was used to analyse the data. The interviews showed that disclosure served different functions for autistic people, including allowing them to access support, to be themselves, and to help others. Autistic people telling others about their diagnosis require them to make decisions about things like how much information to disclosure and to think about feelings and reactions of others. Some people started telling others about their potential diagnosis even before a formal diagnosis is received. There are both good and bad sides of disclosure. Some are positive experiences, like feeling accepted and finding a community. However, sometimes experiences can be negative, such as people not believing them, and these are often because of people have assumptions about autism. These experiences could also be emotionally challenging for autistic people and can also stop autistic people from having their needs met. Autistic people varied greatly on the support they received around disclosure and more consistent post-diagnostic support is needed.

Acknowledgements

This thesis is dedicated to the autism community and the autistic people who have contributed to this work.

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Chapter One: Systematic Review

Post-diagnostic psycho-education interventions for autistic adults without intellectual disability: A Narrative Systematic Review of Quantitative Studies

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Abstract

Psychoeducation is a common component of psychotherapy used to increase a person's understanding their own mental health condition. Some autism assessment services within the UK routinely offer psychoeducation adapted for autistic adults as a form of post-diagnostic support, however, effectiveness of these interventions had not been systematically reviewed. This systematic review investigated whether interventions including an autism psychoeducation component designed for autistic adults without a learning disability are effective at improving mental health outcomes, including depression, anxiety, quality of life, self-esteem, knowledge, and acceptance of autism diagnosis. A total of 18120 records were identified through five databases: MEDLINE, PsychINFO, Scopus, Web of Science, and CINAHL in May 2023. After deduplication and the screening process, 20 studies involving 666 autistic participants met inclusion criteria. The QualSyst tool (Kmet et al., 2004) was used to assess the quality of the studies. Standalone psychoeducation interventions and those combining psychoeducation with common psychotherapeutic interventions, such as mindfulness-based therapies and CBT, showed some promising effects for improving depression, anxiety, quality of life. However, there was high heterogeneity between study designs, comparison group used, and insufficient sample size in many studies. A small number of studies reported self-esteem, knowledge, and acceptance as outcome measures, and although some preliminary positive effects were shown for knowledge and acceptance, there are risks of measurement and misclassification error due to the use to unvalidated measures. Furthermore, only a minority of studies involved autistic people in the design and delivery of the interventions which is a limitation. There is preliminary evidence that autism psychoeducation post-diagnosis improves

mental health outcomes for autistic people when offered alone or in combination with another type of psychotherapy, but there is not currently a robust evidence base in this area and no conclusions can currently be drawn on the most effective mode of delivery.

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Practitioner Points

- Autism psychoeducation intervention offered post-diagnostically should be routinely evaluated to accumulate more evidence for its effectiveness.
- Services should involve autistic people in the design and delivery of psychoeducational interventions, where possible.
- It remains to be tested whether standalone psychoeducation or combined interventions, or taking strength-based approaches, could be of greater benefit to autistic people.

Keywords: Autism, Psycho-Education, Post-Diagnostic, Quantitative, Systematic Review, Narrative Review, Adults

Introduction

Autism is a life-long neurodevelopmental condition characterised by difficulties in social communication and restrictive, repetitive, stereotypical patterns of behaviour, interests, and activities (DSM- 5, American Psychiatric Association, 2013). In the UK, an increasing number of people, particularly women, are receiving autism diagnoses in adulthood (Russell et al., 2022). Potential contributors to this phenomenon may include increasing public awareness of autism (Russell et al., 2021), broadening of the diagnostic criteria (DSM-5; APA, 2013), and the development of adult autism diagnostic pathways in the UK national health service (Department of Health, 2015). The *Autism Act* (UK Government, 2009) committed the British government to publish a strategy for improving services for autistic people in the UK, which was recently reviewed in 2021. The revised strategy stated six main areas of improvement required. These were improving public understanding of autism, helping autistic people in education, helping autistic people to seek employment, equality in healthcare, support within the community, and support within the justice system (UK Government, 2021). The National Institute of Health and Care Excellence (NICE, 2021) recommended the establishment of specialist autism teams with a multidisciplinary setup in each locality to offer post-diagnostic support for autistic people in some of these key areas (NICE, 2021).

While the need for post-diagnostic support is clear, there is currently a lack of clear and detailed national guidance on how autistic adults should be supported to make sense of their diagnosis and manage its psychological impact. NICE (2021) stated briefly that newly diagnosed autistic adults “should be offered a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require” [CG1421

Section 2.18]. This limited guidance on what good practice should look like means that post-diagnostic support varies greatly nationally (Beresford et al., 2020).

Psychoeducation is a type of intervention which involves providing information about a condition to a person, typically the person being diagnosed with the condition or their loved ones (Bankovska Motlova et al., 2017). Psychoeducation can be delivered in different formats, such as individual or group, as a stand-alone intervention, or as a component of another psychological treatment programme. Psychoeducation had been incorporated into psychotherapy treatment programmes to give people an understanding of their symptoms and psychological processes involved in the maintenance of their problems to help promote change (e.g. CBT; Beck, 2021). Existing systematic reviews on the impact of psychoeducation support its use for a range of mental health problems such as depression and schizophrenia (e.g. Tursi et al., 2013; Xia et al., 2011).

Psychoeducation interventions for newly diagnosed autistic adults are often developed in-house, independently, by services, and service evaluations of such interventions are scarce due to service pressures (Beresford & Mukherjee, 2023). It is therefore unclear whether these interventions are effective at improving psychological outcomes for autistic adults. Furthermore, given the vast availability of information now accessible on the internet, people accessing diagnostic service are likely to have come across information about autism via their own research, therefore it is unclear whether post-diagnostic psychoeducation could offer additional value for autistic people. However, recent Delphi studies (Crowson et al., 2023; Wigham et al., 2023) showed that support to help process the impact of a diagnosis is amongst the top post-diagnostic priorities for autistic adults, and psychoeducation intervention may be able to serve this function.

To the best of the author's knowledge, there was no published systematic review *specifically* on autism psychoeducation for autistic adults without intellectual disabilities. Other reviews in this general area include a systematic review by Davis et al. (2019) investigated the effectiveness of "psychoeducational interventions" for improving behavioural outcomes for adults with level 3 autism who require very substantial support and likely co-occurring intellectual disability. However, this study defines psychoeducation as behavioural modification interventions, such as applied behavioural analysis, rather than interventions focussed on learning about and accepting an autism diagnosis.

A systematic review by Lorenc et al. (2018) investigated the effects of support more generally for autistic adults without intellectual disabilities One category of support they reported was "Social Skills Training and Psychoeducation" for which 22 studies in total were found. However, the review indicated that only three of these studies (Hesselmark; 2014, Eack et al., 2013, White et al., 2016; as cited in Table 1 of Lorenc et al., 2018) contained elements of psychoeducation and it was unclear whether these were psychoeducation about autism. Lorenc et al. found that Social Skills and Psychoeducation training generally had positive effects on social outcomes, though their effects on quality of life and mental health outcomes were missed and inconclusive.

Finally, Ağırkan et al. (2023) reviewed group-based psychoeducation programmes in Turkey for parents of autistic children found positive effects on parents' psychological symptoms (medium), social skills (low), and high effects on wellbeing (high). Similarly, a systematic review of randomised controlled trials of s psychoeducation parenting support by Kholidah et al. (2018) found a reduction in parental stress and improvements in other parenting related outcomes. However,

neither review reported the impact of the interventions on the autistic children themselves. Psychoeducational needs of autistic adults without intellectual disabilities are likely to differ from autistic people with co-occurring intellectual disabilities, autistic children, and their parents. Evidence is needed to establish whether post-diagnostic intervention programme involving autism psychoeducation would benefit autistic adults without intellectual disability.

Objectives

The primary aim of the current review is to gain an understanding of whether autism psychoeducation interventions have a positive effect on mental health outcomes for autistic adults without intellectual disabilities. Several relevant psychological outcome measures were selected for review, including 1) depression, 2) anxiety, 3) self-esteem, 4) quality of life, 5) knowledge of autism, and, 6) acceptance of diagnosis. Depression and anxiety were selected as autistic people report these to be commonly diagnosed mental health problems for them (Au-Yeung et al., 2019). Further, understanding which interventions could help reduce mental health problems, including anxiety and depression, were named the top priorities for autism research by autistic people and their allies (James Lind Alliance, 2016). Self-esteem and Quality of Life were selected as autistic people generally reported lower self-esteem and quality of life compared to their typically developing peers and the general population (Cooper et al., 2017; Mason et al., 2018). Psycho-educational interventions may help elevate self-esteem in autistic people through fostering a positive autism identity and improved quality of life through various indirect mechanisms, such as access of support and improved mental health. Knowledge and acceptance of autism diagnosis were also included as outcome measures given that the key goals of psychoeducational interventions were “to educate, support

acceptance, and empower newly diagnosed people" (Beresford & Mukherjee, 2023; p. 9) hence it was deemed important to assess whether psycho-education interventions are meeting their intended goals for autistic adults

Method

Study Design

I conducted and reported this systematic review following the guidelines for the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA, (Page et al., 2021). A PRISMA checklist is available in Appendix A. A registered protocol is available in the International Prospective Register of Systematic Reviews (PROSPERO, CRD42023391059). The current report is part of a wider review which looked both quantitative and qualitative studies of psychoeducation interventions for autistic adults without intellectual disabilities, only studies involving quantitative data are reported here. Qualitative studies will be reported separately for publication purpose of the wider project.

Search Strategy

Five databases: MEDLINE (via OvidSP), PsychINFO (via OvidSP), Scopus, Web of Science, CINAHL (via EBSCO) were searched to identify potential articles for the review in May 2023. The following combination of search terms were used to search Titles and Abstracts fields within the databases.

1. Autis* OR Asperger* OR Pervasive developmental disorder*

2. Adult* OR Men OR Man OR Women OR Woman

3. psychoeducation* OR psycho-education* OR program* OR intervention* OR support*

Criteria 1 to 3 were combined using the AND operator. Due to differences in the interface between databases, the search strategy was adapted slightly for different databases (See Appendix B for search strategy for each database).

Protocol Deviations

Originally the databases were searched (January 2023) using an additional criterion ("diagnos*") to the search terms in accordance to the original version of the protocol. However, this resulted in only four potentially eligible articles for full-text review. Therefore, this criterion was removed for the search reported in this review which resulted in a larger number of eligible articles.

Study Selection

Only articles published in English were included in the search. Reference lists of eligible articles that met the eligibility criteria and relevant review articles were also searched manually for any additional eligible articles.

Articles describing original empirical research studies evaluating post-diagnostic interventions including a psycho-education component on understanding an autism diagnosis delivered to autistic adults without intellectual disability were included in the review. A broad range of articles were included, including peer-review journals, preprints, unpublished thesis, book chapters, as long as the article reported an original empirical study involving an intervention with quantitative outcome data. Interventions aimed to promote understanding and acceptance of an autism diagnosis, including educating an individual and providing information about their condition to help them manage it more effectively. Format of the interventions could include but were not limited to: in-person, remote, one-to-one, group based, or self-

help interventions. Comparators could include treatment as usual/waiting list/alternative intervention/ non-intervention control. Studies presenting only a single condition of psychoeducation intervention with no comparators/control group were also included. The eligibility criteria are listed below:

Inclusion Criteria

- Autistic adults as diagnosed using any recognised diagnostic criteria (age 18 years or above)
- Participated in an intervention in adulthood
- Intervention must include a psychoeducational element on autism diagnosis
- No Intellectual Disability
- The full-text article must be reported in the English language
- Reported quantitative findings

Exclusion Criteria

- Applied Behavioural Analysis type interventions (excluded due to ethical concerns (Anderson et al., 2022; Bottoma-Beutel & Crowley, 2021; Shkedy et al., 2021)).
- medical interventions (such as pharmacological treatment)
- Articles such as systematic reviews, editorials, letters or articles that do not include original data (although systematic reviews with potentially relevant articles were checked for additional relevant articles)
- Studies of interventions solely aimed at family members/carers/ professionals were excluded unless autistic people themselves were participants of the intervention.

Note that if studies included some participants who don't meet the inclusion due to their characteristics (e.g. age, IQ, diagnostic status), the studies would be still be included if it was possible to separate out results for those who do and do not meet the inclusion criteria. Studies that do not report these characteristics were excluded.

Screening

References retrieved from each database were exported and merged into one master list in Zotero. Any duplications were first removed using a semi-automated deduplication function in Zotero. The full-list of articles were then uploaded onto Rayyan, an online application which allows collaborators to simultaneously complete the screening procedures. The list of articles was checked on Rayyan for any remaining duplicates which were then manually removed.

A two-stage approach was used for the screening process. First, Titles were screened against the inclusion and exclusion criteria followed by abstracts. During screening, all records were independently reviewed by two reviewers (SAY and SC). Titles were either marked as "maybe" or "exclude" by each reviewer. If at least one of the reviewers marked the record as "maybe", the record was moved to the abstract review stage. Similarly, at the abstract screening stage, any records that was marked with at least one "maybe" was moved into the full-text review stage. This cautious approach was taken to avoid missing any potentially relevant articles early in the review process. Any records that were marked with "exclude" by both reviewers either at the title or abstract screening stage were excluded from the review.

Full-text review of remaining articles were completed by the first reviewer to determine eligibility. If after screening the full-text it was still unsure whether an article should be included, the article was further screened by another reviewer (MF

or DP). Decisions were then discussed during a consensus meeting with all three reviewers (SAY, MF, DP) with any disagreements resolved.

Data Extraction

Tables summarising characteristics of the included studies were created. The lead author read each article in detail to extract key information, including author, year of publication, country, whether a preregistered protocol was available, study design, intervention, duration comparator, and participant characteristics (number of participants, gender, age, details of autism diagnosis and IQ). Separate results tables were presented for each target outcome measures to allow narrative summary of the effects of the interventions on each outcome measure. The target measures included depression, anxiety, quality of life, self-esteem, knowledge, and acceptance of autism diagnosis. The results tables identified the study authors, year of publication, outcome measure used, and summary of the quantitative finding, including *p*-value and effect sizes where available.

Quality Appraisal

The Standard Quality Assessment Criteria Checklists (QualSyst: Kmet et al., 2004) was used to assess quality of studies included in this review. This tool was selected as it contains separate checklists for both quantitative and qualitative studies which are suitable for use for evaluating primary research from different fields and it was anticipated available studies would vary greatly in terms of methodology and design**.** The quantitative checklists included 14 items respectively evaluating internal study validity. Responses were rated as either Yes, Partial, No, or Not Applicable for some items of the quantitative checklist. Evaluation of the

QualSyst tool found that by-item interrater agreement ranged from 73-100% for the quantitative checklist.

Consensus

Twenty percent (Five articles) of the included articles were randomly selected using an R script (see Appendix C) developed by DP for quality appraisal consensus check by a second review (either DP or MF). Any inconsistencies were discussed and resolved between the raters.

Results

Search Findings

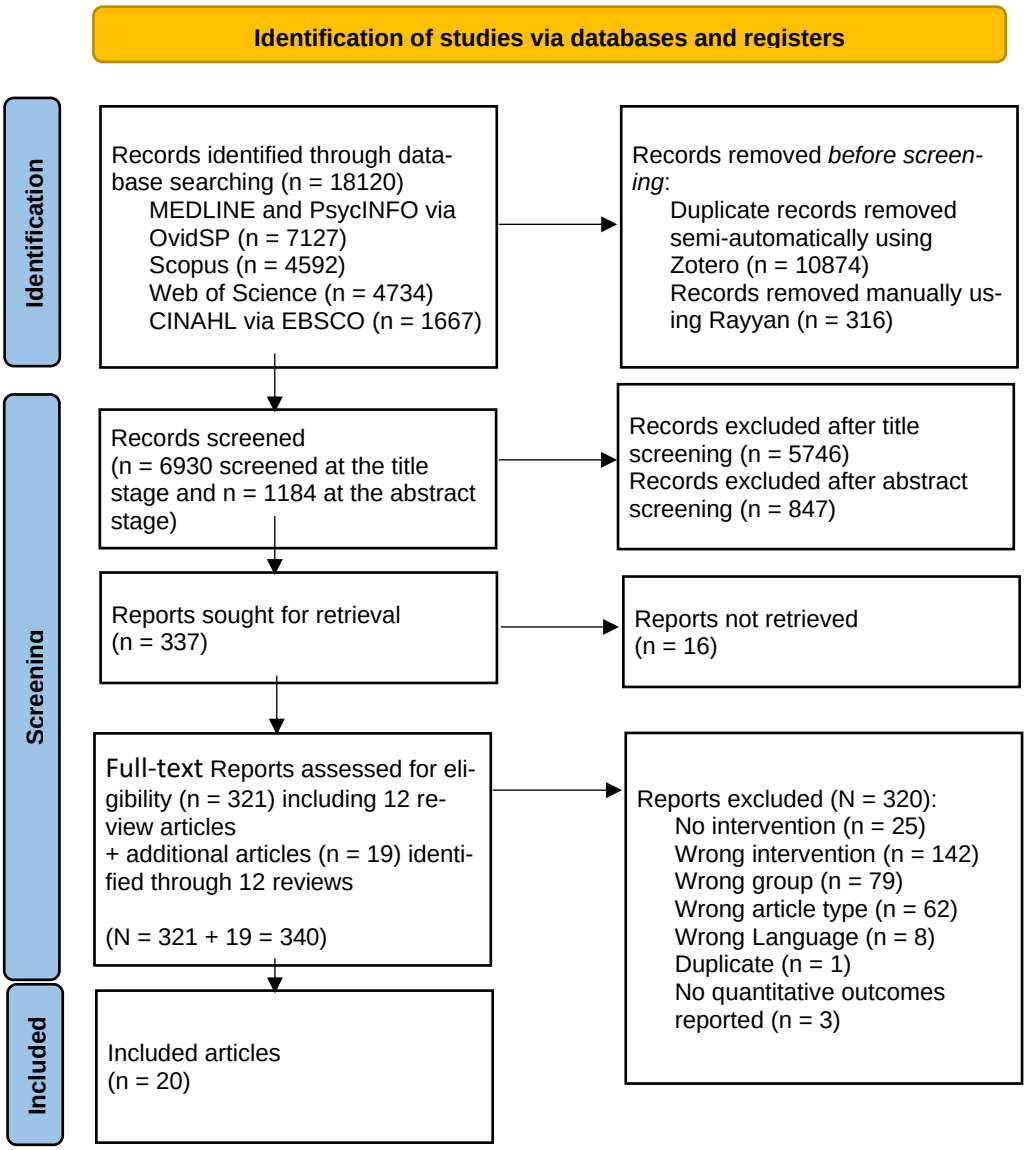
Figure 1 shows the PRISMA flowchart for the studies identified through the search. Percentage of agreement between the two reviewers SA-Y and SC at the title screening stage and abstract screening stage were 88% and 89% respectively. Search from the six databases yielded 18120 records. After automatic and manual deduplication removing a total of 11190 records, 6930 records were screened at the title stage and 1184 records were screened at the abstract stage. 340 available full-text articles were reviewed which included 321 articles resulting from the double screening stages and an additional 19 articles identified through full-text review of systematic review articles arising from our search. Finally, 20 eligible articles were identified to meet eligibility for the current review.

Excluded Studies

At the full-text review stage, 320 articles were excluded. In terms of studies that might appear to meet the inclusion criteria, but which were excluded: three studies reported qualitative findings only (Hatton & Lee, 2021; Westerberg et al., 2021; Locke et al., 2023); and three studies included some participants who did not meet the eligible criteria of this review due to a lack of formal autism diagnosis

(Crane et al., 2021; also reported qualitative findings only), being under the age of 18 (Sehlin et al., 2018), or having an intellectual disability (Yokoi et al., 2014), and it was impossible to separate out the data for the participants within these studies who do met the criteria. Data from the “Support-Only” group in Beresford et al. (2020) were not reported in this review due to this group included participants under the age of 18, however, data from comparisons between the Diagnosis & Support Group (receiving diagnosis and post-diagnosis support) and Diagnosis-Only group were included as all participants in these groups met the age criterion for this review.

Figure 1. PRISMA flowchart



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Characteristics of Included Studies

Characteristics of all included studies are summarised in Table 1. Of included articles, there were seven randomised controlled trials (Ashman et al., 2017; Hesselmark et al., 2014; Kiep et al. 2014; Kuroda et al., 2022; Oswald et al., 2018; Smith DaWalt et al., 2021; Spek et al., 2013; White et al., 2016), one observational study (Beresford et al., 2020), seven uncontrolled feasibility/pilot type experimental studies (Eack et al., 2013; Hidalgo et al., 2022; Howlin & Yates et al., 1999; Krämer et al., 2021; McDonald e al., 2023; Oshima et al., 2021; Spain & Blainey, 2017), and four multiple single case experimental studies (Groenendijk et al., 2023; Helverschou et al., 2019; Pugliese & White, 2014; Rodgers et al., 2018). Two studies were completed in Japan (Kuroda et al. 2022; Oshima et al., 2021) with the rest being completed in Europe and the USA. One study (Kuroda et al., 2022) had an accessible published protocol (Kuroda et al., 2013). One study reported a publicly available online protocol but is no longer retrievable (Beresford et al., 2020); Two reported pre-registration of the trials but protocols were not available online (Groenendijk et al., 2023; Oshima et al., 2021); one study was retrospective registered (Hidalgo et al., 2022); while the rest did not report pre-registration or a published protocol.

Most studies included autism psychoeducation as a part of another type of intervention, including social skills group (Ashman et al., 2017; Howlin & Yates (1999), cognitive enhancement therapy (Eack et al., 2013), cognitive behavioural based therapies (Helverschou et al. 2019; Hesselmark et al., 2014; Kuroda et al. 2022, Oshima et al., 2021; Pugliese & White, 2014; Rodgers et al., 2018; Spain & Blainey, 2017; White et al., 2016), Mindfulness based therapy (Kiep, 2014; Spek et al. 2013), Mentalisation based Treatment (Krämer et al. (2021), Multi-component

Programmes (McDonald et al., 2023; Oswald et al., 2018). Only three studies reported autism psychoeducation as the main intervention of their study (Beresford et al., 2020; Groenendijk et al., 2023; Hidalgo et al., 2022; Smith DaWalt et al., 2021). Furthermore, only four studies clearly reported involvement of autistic people in either the co-design and/or the co-delivery of their interventions Groenendijk et al., 2023; McDonald e al., 2023; Oswald et al. 2018; Smith DaWalt et al., 2021).

Table 1. Characteristics of included studies

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
Ashman et al. (2017) Scotland No	Pilot Randomised Controlled Trial between-group repeated measures	Social Skills Group (include psychoeducation on theories of ASD, relating own difficulties to theories, and language issues in ASD), and disclosure *No/No*	1 hour sessions delivered weekly over 16 weeks	Social Intervention Group (Active control)	Total *N* = 19 adults. Social skills Group: *n* = 10 Social Interaction Group: *n* =9	Social skills Group: *M* =36.1, *SD* =12.0, range 22-61 Social Interaction Group: *M* = 31.78, SD = 13, range 19-55	(Male;Female) Social skills Group 70%;30% Social Interaction Group: 67%;33%	Previous clinical diagnosis of ICD-10 Asperger Syndrome (World Health Organisation, 1994). No standardised diagnostic tools used.	WASI: Social skills Group: *M* = 109, SD = 19, Social Interaction Group: *M* = 103.6, SD = 23.8).
Beresford et al. (2020)[M] (Chapter 8) England Protocol mentioned in publication but no longer publicly available on website	Observational study , repeated measures Between-group repeated measures	Specialist Autism Teams Cohort subgroup who received both Diagnosis and ongoing support[a] Specialist Autism Teams offered post-diagnostic psychoeducation intervention either in individual or group format, integrating psychotherapeutic and educational elements to develop understanding and acceptance of autism, address information needs, and support the development of adaptive strategies to manage everyday life. *Likely varied/likely varied*	Varied across teams, some were multisession group intervention, some were two or more individual sessions, some offered flexibility regarding mode of delivery based on the individual's needs.	The Diagnosis-Only cohort which comprised of individuals from out-of-area who accessed diagnostic assessment but did not receive post-diagnosis support from Specialist Autism Teams	Diagnosis and Support Group: *n* = 133 DO cohort: *n* = 52 (Based on Retention at Time 3 (primary follow-up timepoint)	Diagnosis and Support Group: *M* 31.1, range = 18-69. Diagnosis-Only Group: *M* = 35.23, range = 18–64	(Male; Female; Neither) Diagnosis and Support Group: 57.1%;39.3%;3.6 Diagnosis Only Cohort: 64.3%; 35.7%;0% (Based on pre-dropout data)	Assessment Protocols varied across different Specialist Autism Teams differed in their diagnostic assessment protocols	All Specialist Autism Team operated an eligibility criterion of IQ > 70 but data not reported
Eack et al. (2013) USA No	Uncontrolled Feasibility study repeated measures	Cognitive Enhancement Therapy integrating computer-based neurocognitive (attention, memory, problem solving) training and social cognitive group (perspective-taking and social context appraisal). Early component of the social cognitive group include psychoeducation on knowledge and understanding of ASD and its impact upon cognition, information processing, social cognitive, sensory perception, and emotional management *No/No*	18 months 60 hours of neurocognitive training 1 hour weekly 45-session social-cognitive group 1.5 hour weekly	-	Total *N* = 14	*M* = 25.29, SD = 5.72	Male: 85.7%	ADOS and ADI-R *n* = 8 met criteria for autism n = 6 met criteria for ASD	WASI FSIQ: *M* = 117.7, *SD* = 16.77, range = 92-157.

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
Groenendijk et al. (2023) Netherlands Registered trial but protocol unavailable online	Multiple case study design	Co-designed psychoeducation program for older autistic adults (55+ years) specifically dealing with aging when autistic delivered in groups of 4-6 with two trainers per group. Yes/No	six weekly meetings of 2h each	-	Total *N*=9, participant and a person close to them (proxy)	*M*=65.00, *SD*=5.59, range = 56–73	(Male;Female) 89%;11%)	Clinical diagnosis of ASD using ADOS	DART or MoCA to confirm IQ >80
Helverschou et al. (2019)[M] Norway No	repeated measures	CBT modified for ASD/ Substance Use Disorder (psychoeducation included but not specified that it's ASD related. Post treatment interview/discussion indicate ASD psychoeducation GENERALLY is often needed) No/No	30--40 sessions lasting between 8 and 25 months (*M* = 17)	-	4	*M* = 31.4, range = 22 - 44	Male = 100%	Clinical diagnosis of ASD (ICD-10). AQ: *M* = 31.8; range: 23-42	WAIS-III or WASI *M*= 110.8. range: 102-125.
Hesselmark et al. (2014) Sweden No	preliminary open randomised controlled trial	CBT led by two therapists in groups of 6-8. CBT include techniques of acceptance and change. CBT intervention included psychoeducation on ASD (Session 3 - What is autism; Session 4 - How does your autism affect you) and psychiatric symptoms, including learning to identify and reappraise maladaptive thoughts, and social training. No/Maybe	36 weekly 3 hour sessions	recreational activity	CBT *n* = 35 Recreational activity A *n* = 40.	CBT *M* = 31.9, *SD* = 8.5, Recreational Activity: *M* = 31.8, *SD* = 9.6. ,	Male % in each group CBT = 49% male, RA = 60% male	clinically diagnosis of ASD, confirmed by medical records and the ADOS, and clinical interviews ADOS total score: CBT: *M* =11.4, *SD* =4.6 RA: *M* =11.1, *SD* = 3.2.	inclusion criteria: having normal intellectual ability as indicated by mainstream schooling and absence of an intellectual disability diagnosis
Hidalgo et al. (2022)[M] Sweden Retrospectively registered on Clinicaltrials.org	Open Feasibility trial	Face-to-face psychoeducational group intervention (PRISMA) aimed to increase knowledge about autism, as well as provide information on how to access further services. face- to -face. Session include: 10 -15 participants with ASD per group and 1-2 close relation per participant No/No	4 weekly 2 hour sessions	-	*N* = 71	*M* = 32.7, *SD* = 12, range = 18–64	Female % 43.6%	Clinical diagnosis of ASD based on DSM-IV, DSM-V, or ICD-10 RAADS: *M* = 26.9, *SD* = 9.74 .	Exclusion criteria: intellectual disability based on pre-intervention screening interview

Author (Year), Country, Preregistered protocol?	**Design**	**Intervention** ***Co-design/Co-delivered?***	**Duration**	**Comparator**	**Participants (*N*)**	**Age (Years)**	**Gender %**	**Autism Diagnosis**	**IQ**
Howlin & Yates (1999) England, UK No	quasi repeated measure	Social Skills Group - aimed to provide better understanding and dealing with social difficulties Session 2 include talk and discussion on 'understanding autism' No/No	Monthly 2.5 hours sessions over the course of a year	-	*N* = 10	*M* = 28.4, range 19-44	Male 100%	Clinical diagnosis of autism or Asperger syndrome	non-verbal IQ was 109 (range 86–138)
Kiep et al. (2014) Netherlands No	repeated measures at baseline (1 week after the start of MBT), assessment of short term effects after 9th session, and assessment of long term effects 9 weeks after the last session	Mindfulness-Based Therapy for individuals on the autism spectrum (MBT-AS) based on Spek (2013). (Groups of 10) No/No	9 weekly sessions of 2.5 hours each, and self-practise of 40-60 minutes of meditation at home 6 days a week	-	*N*=50. Included the data of 20 participants from Spek et al. (2013).	Male: *M* =42.1, *SD* = 10.5 Female: *M* = 37.9, *SD*=14	Male;Female 68%;32%	Clinical diagnosis of ASD based on DSM-IV-TR using semi-structured interview ((e.g., Spek et al., 2008, 2009), and Dutch ADI-R	Exclusion Criteria: below-average FSIQ (IQ <85) and below average Verbal IQ (<85) as measured by the WAIS-III
Krämer et al. (2021)[M] Germany No	repeated measure, quasi	Adapted Mentalization-Based Treatment for adults with ASD (MBT-ASD). During four introductory sessions, participants were educated about ASD, mentalizing, emotions, and MBT methods. Psychodynamic based. Group based (2 groups). No/No	Weekly sessions of 90 minutes for 15 -20 weeks Group 2 constrained to 15 weeks due to COVID-19	-	*N* = 16 (8 in each group)	MBT-Group 1: *M*=43.50, *SD*= 8.54 MBT-Group 2: *M*=46.63, *SD*= 12.58	Male;Female Group 1: 50%;50% Group 2: 75%;25%	Clinical Diagnosis of Asperger's Syndrome based on ICD-10.	Intelligence was assessed by a German multiple choice vocabulary test (WST) Group 1: *M* =110.63, *SD* =10.86 Group 2: *M* =115.00, *SD* =5.88
Kuroda et al. (2022) Japan pre-registered but full published	single-blinded randomised controlled trial	group-based CBT for emotion regulation with psychoeducation about ASD. Psychoeducation included lectures and discussions of diagnosis, epidemiology, aetiology, symptoms and characterization, daily life.	100-minute weekly sessions over 8 weeks	Waiting List Control	CBT *n* = 29 Waitlist *n* = 29	CBT: *M* =29.6, *SD*=8.0 Waitlist: *M*= 29.6 ± 8.0	Male;Female CBT:66%;34% Waitlist:72%;28 %	DSM-IV-TR diagnosis of PDDs based on ADOS; ADI-R; Japanese versions of AQ;	WAIS-III FSIQ: CBT *M* =110.2, *SD* = 12.9, Waitlist *M*

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
protocol not available		No/No						SRS-A; SCQ; ESQ).	= 104.9, *SD* = 11.9
								ADOS: Communication CBT: *M* = 3.2, SD =1.3, Waitlist: *M*= 3.4, *SD*= 1.2; Social Interaction: CBT *M* = 7.0, SD=1.6);WL: *M* = 7.3, SD=1.9 ADI-R Communication: CBT *M* = 9.7, *SD*= 5.0, Waitlist *M* = 8.8, *SD* = 4.2 Social Interaction CBT: *M*=12.0, *SD*=6.2; Waitlist *M*=12.2,SD=5.7; Repetitive behaviours: CBT *M* =3.3, *SD*=1.9; Waitlist: *M*= 3.3, *SD*=1.7	VIQ: CBT = *M* = 114.8, *SD* =14.7, Waitlist *M* = 109.2, *SD* = 11.9 PIQ: CBT *M*=102.6, *SD*=15.1; Waitlist: *M* = 98.0, *SD* = 15.4
McDonald e al. (2023)[M] USA No	repeated measures	Multi-component Self-determination Program addressing goal development, self-determination, self-advocacy, disclosure, active listening, conflict resolution, mindfulness, and community living and is based on evidence-based programs including Self Determination Learning Model of Instruction, Goal Attainment Scaling, Mindfulness-based Stress reduction, and peer-coaching.	5-day immersion phase to learn goal attainment skills and develop initial goals. 3 months coaching phase - participants met with peer coaches to discuss progress on goals	-	31	Range: 18-34 Male:*M* =23.85, *SD* =3.80 Female: *M* =24.55, *SD*=5.72	Male;Female 65%:35%	clinical or education diagnosis of autism assessed by ADOS-2 pre- or during study	WASI-II pre or during study Male: *M* = 104.75 , *SD* =14.97 Female: *M* = 95.64, *SD* =16.83

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
		Delivered in 4 groups of 8 participants each) This study combined several evidence-based interventions Yes/Yes – autistic people involved in design and co-teaching	and identify next steps. Follow-up phase - social events for participants.						
Oshima et al. (2021) Japan trial registration available but not protocol	Open trial design single-arm uncontrolled trial	Schema Therapy (CBT based) to address chronic psychological maladjustment by making adaptions to live with ASD Include psychoeducation session on "What is ASD?" and "What are the characteristics of my ASD?" based on assessment tests. Also learning about secondary disabilities of ASD. Phase 2 – to learn about difficulties created by friction between autistic traits and environment and performing behaviours that reduces difficulties in their lives.	weekly session lasting 50 minutes each	-	10	*M* = 26.8, *SD* = 6.39, range = 20 -39	Male;Female 50%:50%	Inclusion criteria: an ASD diagnosis based on ADI-R or ADOS-II Participants met DSM-5 criteria for ASD	Inclusion criteria: IQ≥80 on WAIS-III
Oswald et al. (2018) USA No	Pilot randomised controlled trial	Acquiring Career, Coping, Executive Control, and Social Skills Program (ACCESS) delivered in 2 identical groups Combining CBT stress and anxiety coping skills, Self-Determination Skills, adaptive & social skills, psychoeducation on ASD and anxiety, and structured vocational activity Yes/No - young adults who previously participated in a previous programme took part in a focus group and provided feedback, which were then incorporated in the ACCESS programme	19 weekly lessons lasting 1.5 hours Vocational activity: 3 hours a week	Waitlist control group (received ACCESS programme 3 months after the two treatment groups had completed the program.	*N* = 41 autistic adults and their social coach (parent/close relative). Treatment group: *n* = 25, Control: *n* = 16	Treatment group: *M* = 24.9, *SD* = 6.1 Control group: *M* =25.5, *SD*=7.1	Male;Female Treatment group: 64%:36% Control group: 75%;25%	community diagnosis of ASD, meeting criteria on the DSM-5 ASD symptom checklist and score in the ASD range on the ADOS-2 ADOS total score: *M* = 12.9, *SD* = 3.6	WASI-II Treatment group: *M* = 101.4, *SD* = 19.4 Control group = *M* = 102.8, *SD* = 14.4
Pugliese & White (2014) USA	pre- to post-treatment	Problem Solving Skills 101 (PSS:101): adapted Group problem solving therapy based on CBT and included	9 sessions	-	*N* = 5	*M* = 21.27 range: 18-23	100% Males	Previous diagnosis of ASD	Cognitive testing within the past years.

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
No	single subject design	psychoeducation about ASD and how it relates to the problem-solving process No/No						(Asperger's Disorder *n* =4 and *n* = 1 with Autistic Disorder) ADOS module 4 completed as part of study: Total range = 10-17	FSIQ range = 111-136, VCI range = 114 – 141 PRI range = 107 - 137
Rodgers et al (2018)[M] UK No	single case experimental design baseline, intervention, follow-up	CUES-A -CBT based manualised treatment programme targeting intolerance of uncertainty adapted for autistic adults. Content included psychoeducation on the relationship between intolerance of uncertainty and characteristics of autism No/No	8-9 weekly 1-hour sessions	-	4	Range = 30-39	Male;Female 75%;25%	Clinical diagnosis of ASD. 1 x ASD *n* = 1 High-functioning Asperger's *n* =1, 2x Asperger's Sydrome *n* = 2 SRS-2A Score from mild to severe. range = 60-84.	Exclusion criteria: the presence of a learning/ intellectual disability. No IQ data reported.
Smith DaWalt et al. (2021) USA No	randomized waitlist control design	Working Together program - multifamily group intervention for adults and their parents involving education on topics relevant to ASD and guided practice in problem-solving. Sessions topics included introduction, goal setting and problem-solving, coping strategies and problem solving, planning for independence, employment, community and relationships, personal safety, and health and wellbeing. Yes/Yes – involved in material creation and intervention implementation. Research team and advisory board included autistic people	t6 months between baseline and follow up 2 individual family joining sessions (1 hour each), 8 weekly parent and adult group sessions, 3 monthly booster sessions (1.5 hours each)	waitlist control (Intervention received after intervention group)	Intervention Group: *n* = 20 (+ family members of autistic adults) *n* = 20 controls	Total: *M* = 21.77, *SD* = 2.94, range =18-30 Intervention group: *M* = 21.63, *SD* = 2.73 Control group: *M* = 21.94, *SD* = 3.26	Male = 65% for both groups	Medical or educational diagnosis of ASD. CARS-2 and SCQ completed as part of study.	WASI-II Intervention group: *M* = 106.79, *SD* = 12.90 Control group: *M* = 110.65, *SD* = 16.82
Spain & Blainey (2017)[M]	Pilot study	Adapted group CBT for low self-esteem including co-developed formulation	8 sessions (7 weekly two-hour sessions,	-	4	*M*= 39 Range = 30-45	100% males	confirmed clinical	WAIS-III

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
England, UK No	repeated measures	incorporating causal mechanism, core ASD characteristics, neuropsychological functioning deficits, and adverse or difficult life experiences. No/No	plus one follow-up session					diagnosis of ASD	VIQ:*M* = 103. *SD*= 8.6, range: 93-108 PIQ: *M* =98.3, SD = 15.1, Range: 83-113 (IQ unavailable for one participant)
Spek et al. (2013) Netherlands No	Randomised controlled trial	Modified Mindfulness-based Therapy for Autism Spectrum Disorders (MBT-AS). Content included sitting meditation. At Week 6, psychoeducation on ruminative thoughts and the relationship with autism was provided Group format of 10-11 patients. Week 6. No/No	9 weekly sessions, 2.5 hours each	Waiting List control	experimental group *n* = 20 control group *n* =21	Experimental Group *M* = 44.4, *SD* =11.1 Control group n = 40.1, SD =11	Male;Female Experimental Group:65%;35% Control Group:66%:34%	Participants met DSM-IV-TR criteria of the autistic disorder, Asperger syndrome or PDD-NOS and were assessed using ADI-R and semi-structured interview (Experimental; Control) Autistic Disorder n = 11;10. Asperger 5;6. PDD-NOS: 4;5.	Exclusion criteria: scoring 85 or less in full scale intelligence and the verbal comprehension index on WAIS-III IQ scores not reported
White et al. (2016)[M] USA No	Pilot randomised controlled trial (feasibility) Endpoint assessments completed 3.5 months after enrolment.	College and Living Success (CLS) - Psychosocial program targeting social competence and self-regulation based on CBT and mindfulness-acceptance based approaches combining individual therapy, social activities to practice skills and exposures, and supportive coaching. Orientation to CLS module include psychoeducation about ASD No/No	CLS - up to 14 weekly therapy sessions, biweekly social outings and supportive coaching on an as-needed basis. Total commitment: 2 hours per week. BCI-ASD: 10 - 14 weekly sessions lasting 15- 30	Brain-Computer Interface for ASD (BCI-ASD) computerised program targeting social competence, including emotion recognition and social interaction skills.	CLS *n* = 4 BCI *n*= 4	CLS: *M* = 20.25, *SD* =1.71, range = 18–22 BCI: *M* =20.75, *SD* =1.71, range= 19–23	Male;Female 62.5%; 37.5%	pre-existing diagnoses of ASD confirmed by ADOS-2 and brief clinical interview	WASI CLS: *M* =115.75, *SD* = 22.28, range =86–140 BCI-ASD: *M* =126.75, *SD* =5.62, range= 121–134

Author (Year), Country, Preregistered protocol?	Design	Intervention *Co-design/Co-delivered?*	Duration	Comparator	Participants (*N*)	Age (Years)	Gender %	Autism Diagnosis	IQ
			minutes. Total time commitment: 40 minutes per week.	Both (CLS and BCI-ASD) were active paradigms. No control group.					

***Notes*.** [M]denote mixed method studies. [a]In the Beresford study, the Specialist Autism Team cohort including a separate participants referred for support-only but already diagnosed with autism from Specialist Autism Team were involved in the study. However, this group included participants under the age of 18 which violated the study eligibility criteria, therefore were excluded from analysis. WASI: Weschler Abbreviated Scale for Intelligence (Wechsler, 1999). ADOS: Autism Diagnostic Observation Schedule (Lord et al., 2000). ADI-R: Autism Diagnostic Interview-R (Lord et al., 1994). FSIQ: Full-Scale Intelligence Quotient; PIQ: Performance Intelligence Quotient. VIQ = Verbal Intelligence Quotient. DART: Dutch Adult Reading Test (Schmand et al., 1991). MoCA: Montreal Cognitive Assessment (Nasreddine et al., 2005). ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th Revision (World Health Organisation, 2015). WAIS-III: Wechsler Adult Intelligence Scale-Third Edition (Wechsler, 1997). ADOS-2: Autism Diagnostic Observation Schedule- Second Edition (Lord et al., 2012). AQ: Autism Quotient (Baron-Cohen et al., 2001; Japanese Version: Wakabayashi et al., 2006). RAADS: The Ritvo Autism Asperger Diagnostic Scale (Eriksson et al., 2013). DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (American Psychiatric Association, 2000). WST: Wortschatztest (Rasch scaling of the Multiple Choice Vocabulary Test; Schmidt & Metzler, 1992). DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (APA 2013). Social Responsive Scale (SRS-A; Japanese version: Takei et al., 2014). Social Communication Questionnaire (SCQ, Rutter et al. 2003 ; Japanese version; Kuroda et al., 2013). Empathizing-Systemizing Quotient (ESQ, Japanese version; Wakabayashi et al., 2007).Wechsler Abbreviated Scale of Intelligence Second Edition (WASI-II; Wechsler, 2011). Social Responsive Scale Second Edition (SRS-2A ; Constantino & Gruber, 2012). Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler et al. 2010).

Psychological Outcome Measures

Outcome measures for depression, anxiety, self-esteem, quality of life, knowledge of autism, and findings from the reported studies are summarised in Table 2 to 7. There were seven studies included in Table 1 above that were quantitative studies but did not report the target outcome measures selected for this review (Ashman et al.,2017; Helverschou et al.,2019; Howlin & Yates, 1999; McDonald e al., 2023; Pugliese & White, 2014; Smith DaWalt et al., 2021; White et al., 2016). These studies reported a range of alternative outcome measures as dependent variables such as autistic traits, general functioning and impairments, social cognition, treatment satisfaction, goal attainment, general improvements, behavioural difficulties, executive functioning, clinical impression, and general distress. Helverschou (2019) used the Hopkins Symptom Checklist-25 (HSCL-25; Derogatis et al., 1974) which measures symptoms of anxiety and depression though did not report results for this measure.

Depression Measures

Nine studies reported findings from depression outcome measures. There were three RCTs, one study comparing CBT vs Recreational Activities (Hesselmark et al., 2014), one comparing CBT with waiting list control (Kuroda et al., 2022) and one comparing Mindfulness based Therapy to Waiting List Control (Spek et al., 2013). There were also six uncontrolled studies with repeated measures design, one using standalone psychoeducation group intervention (Hidalgo et al., 2022), one using Mentalization-based treatment (Krämer et al., 2021), one using Schema Therapy (CBT based: Oshima et al., 2021), two using CBT (Rodgers et al., 2018; Spain & Blainey, 2017), and one study (Kiep et al., 2014) reporting follow-up data

from the RCT by Spek et al. (2013) using Mindfulness based Therapy but without the control group.

All studies used outcome measures with known psychometric properties. Three studies (Hesselmark et al., 2014; Krämer et al., 2021; Oshima et al., 2021) measured depression severity using the Beck Depression Inventory (Beck et al., 1996; Hautzinger et al.,1995); two studies (Hidalgo et al., 2022; Spain & Blainey, 2017) used the Hospital Anxiety and Depression Scale depression subscale (Sigmond & Snaith, 1983), and two used the Symptom Checklist-90-Revised (Kiep et al., 2014; Spek et al., 2013), one used the Patient Health Questionnaire-9 (Martin et al., 2016), and one study (Kuroda et al., 2022) used the Centre for Epidemiologic Studies Depression Scale (Shima, 1998).

Results from the randomised controlled trials showed that CBT-type interventions did not lead to a reduction in depression severity, and they were not superior compared to active control using recreational activities (Hesselmark et al., 2014) nor waiting list control (Kuroda et al., 2022). In contrast, the RCT by Spek et al. (2013) showed that Mindfulness-base Therapy was superior to waiting list control for improving depression with medium to large effect, and follow-up study on the treatment group showed that improvements were maintained at follow-up with large effect (Kiep et al., 2014). Uncontrolled studies with small sample sizes (Rodgers et al., 2018; Spain & Blainey, 2017; Oshima et al., 2021) reporting CBT-based interventions using repeated measures design reported some improvements in depression, though these were not consistent across participants (Rodgers et al., 2018) not maintained at follow-up (Spain & Blainey, 2017), nor significant after correcting for multiple comparisons (Oshima et al., 2021). An uncontrolled study using standalone psychoeducation group intervention showed improvements in

depression with small effect (Hidalgo et al., 2022), whereas mentalisation-based treatment showed worsening of depression symptoms with medium effect (Krämer et al., (2021).

Table 2. Summary of Findings for Studies reporting measures on Depression

Study	Depression Outcome Measure	Summary of Findings
Hesselmark et al. (2014)	Beck Depression Inventory (BDI; Beck et al., 1996a)	**CBT vs Recreational Activities** No significant difference between pre- and post – treatment for the CBT group (d = .04, Mean difference = .35 (95% CI = -2.28, 2.99) No significant difference between pre- and post – treatment for the Recreational Activities group (d = .11, Mean difference = 1.15 (95% CI = -3.87, 6.18) Between group comparison (*p* =.76)
Hidalgo et al. (2022)	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) - depression subscale	**Pre- and post- Psychoeducation Group Intervention** Depression significantly decreased for participants with ASD (p value<.05, d =.18 5% 95% CI = -.17, -.52, small effect size))
Kiep et al. (2014)	Symptom Checklist-90-Revised (SCL-90-R) depression subscale (Derogatis, 1994)	**Pre- vs Post Mindfulness based Therapy** **MANOVA** Significant main effect of time on depression (*p*<0.001, ηp^2=0.215) indicating level of depression reduced from pre- to post- MBT-ASD. No difference was found between end of therapy and 9 weeks post therapy (*p* =.391). **Correction between Depression and Rumination** Change in rumination was found to be significantly correlated with depression symptoms (*p*=0.031) between pre- and post- MBT-ASD, and between post- MBT-ASD and 9 weeks after (*p*<0.01). **MANCOVA** When rumination was added as a covariate, the difference between pre- and post- MBT-ASD was no longer significant (*p*= 0.569, ηp^2=0.011), indicating that rumination completely mediated the relationship between time and depression. With regards to the difference between immediately post-MBT-ASD and 9 weeks after therapy, the MANOVA shows that the time interaction effect was significant after adding rumination as covariate: (*p*=0.001, ηp^2= 0.153).

Krämer et al. (2021)	German edition of the Beck Depression Inventory (BDI) (Hautzinger et al.,1995)	**Pre vs Post Mentalization-based Treatment** Participants showed increased in depression symptoms (p = 0.040, d = 0.56).
Kuroda et al. (2022)	Center for Epidemiologic Studies Depression Scale (CES-D; Shima, 1998).	**Group based CBT for Emotional Regulation + Psychoeducation vs Waitlist** **Baseline comparison:** No significant differences in pre-intervention assessments in CES-D scores between the CBT and Waitlist groups (p =.11, d = -.42). **Intervention Period Change**: No significant between-group differences (p =.42, d= -.23). **Study Period Change**: No significant between-group differences (p= .45, d = .21).
Oshima et al. (2021)	Beck Depression Inventory II (BDI-II, Beck et al., 1996b)	**Comparison between pre-, post-, and follow-up for Schema Therapy (CBT-based)** **rANOVA:** Significant effect of time was observed for BDI-II (p <.01, decreasing trend); however, post hoc comparison with Bonferroni correction did not remain significant between each time point (alpha = .0007, ps not reported, d = .70, .29,.99 respectively for pre-ST vs post-ST, Post-ST vs follow-up, and pre-ST vs follow-up).
Rodgers et al (2018)	Patient Health Questionnaire-9 (PHQ-9; Martin et al. 2006)	**CBT (Pre-intervention vs follow-up)** **Reliable and Clinical Significant Change** 2 participants showed significant improvement (moving from above to below the clinical cut-off); 2 participants showed no change (one remained above clinical cut-off and the other was already below cut-off pre-intervention).
Spain & Blainey (2017)	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) - depression subscale	**CBT (Baseline vs First session vs Last session vs follow-up)** Depression symptoms improved from the moderate to the mild range over the course of intervention, but this was not maintained at follow-up. (means were above clinical cut-off for all timepoints. Descriptive statistics reported only due to small sample size).
Spek et al. (2013)	The Symptom Checklist-90-revised (SCL-90-R)	**Mindfulness-based Therapy vs Waiting List Control**

depression subscale (Derogatis, 1994)	**MANOVA comparing pre- and post-intervention between groups on 4 outcomes (including depression)** Significant main effect of Time and Time x Group Interaction (p = .003, ηp^2 = 0.35; p = .001, ηp^2 = 0.38). **ANOVA for depression** Significant main effect of time (p < .05, ηp^2 > 0.97) and significant Time by Group interactions: depressive symptoms (p = .02, ηp^2= 0.14). The mindfulness-based therapy group showed greater reduction in depression symptoms compared to waiting list control group based on examination of means (effect size for between group difference on change scores d = .78 medium-large effect). **Correlation with Rumination (The Rumination-Reflection Questionnaire (RRQ, Trapnell & Campbell, 1999)** There was a significant correlation between change in rumination and change in depressive symptoms across groups (p = .03). **MANOVA with change in rumination as covariate** Time x Group interaction no longer significant for depressive symptoms (p > .10, ηp^2 = 0.06). However, a test of mediation showed that the indirect effect not significant for depressive symptoms (95% CI= -4.94 to +2.11, p > .10). These results suggest reduction in depression may be partly attributed to reduction in rumination.

Anxiety

Eight studies reported findings from anxiety outcome measures. There were three RCTs, one comparing CBT with waiting list control (Kuroda et al., 2022) one comparing Mindfulness based Therapy to waiting list control (Spek et al., 2013), and one comparing a multi-component intervention (ACCESS) to waiting list control (Oswald et al., 2018). There were also five uncontrolled studies with repeated measures design, one using standalone psychoeducation group intervention (Hidalgo et al., 2022), one using Schema Therapy (CBT based: Oshima et al., 2021), two using CBT (Rodgers et al., 2018; Spain & Blainey, 2017), and one study (Kiep et al., 2014) reporting follow-up data from the RCT by Spek et al. (2013) using Mindfulness based Therapy but without the control group.

All studies used outcome measures with known psychometric properties. **T**wo studies (Hidalgo et al., 2022; Spain & Blainey, 2017) measured anxiety severity using the Hospital Anxiety and Depression Scale anxiety subscale (Sigmond & Snaith, 1983), two (Kiep et al., 2014; Spek et al., 2013) used the Symptom Checklist-90-Revised anxiety subscale (Derogatis, 1994), two (Kuroda et al., 2022; Oshima et al. (2021) used the State-Trait Anxiety Inventory (Spielberger et al. 1970; Suzuki et al., 2000), one (Oswald et al., 2018) used the ASEBA Adult Self-Report DSM-oriented scale for Anxiety Problems (Achenbach & Rescorla, 2003), and one (Rodgers et al., 2018) used the Generalised Anxiety Disorder-7 scale (Spitzer et al., 2006).

Results from the randomised controlled trials showed that both CBT (Kuroda et al.,2022) and ACCESS (Oswald et al., 2018) showed no difference to waiting list control, whereas Mindfulness based Therapy was superior to waiting list control for reducing anxiety with medium effect (Spek et al., 2013), and follow-up study on the

treatment group showed that improvements were maintained at follow-up with large effect (Kiep et al., 2014). Uncontrolled studies with small sample sizes reporting CBT-based interventions using repeated measures design reported some improvements in anxiety, though these were not consistent across participants (Rodgers et al., 2018) not maintained at follow-up (Spain & Blainey, 2017), nor significant after correcting for multiple comparisons (Oshima et al., 2021). An uncontrolled study using standalone psychoeducation group intervention showed improvements in anxiety with small effect (Hidalgo et al., (2022).

Table 3. Summary of Findings for Studies reporting measures on Anxiety

Study	Anxiety Outcome Measure	Summary of Findings
Hidalgo et al. (2022)	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) - anxiety subscale	**Pre- vs Post Psychoeducational Group Interventions** Anxiety significantly decreased for participants with ASD) ($p < .01$, $d = .21$, 95% CI = -.13, -.55, small effect size)
Kiep et al. (2014)	The Symptom Checklist-90-revised (SCL-90-R) anxiety subscale (Derogatis, 1994)	**MANOVA (Pre- vs Post Mindfulness-Based Therapy)** Significant main effect of time on anxiety (p=0.001, ηp^2=0.185), indicating level of anxiety reduced from pre- to post- MBT-ASD. No difference was found between end of therapy and 9 weeks post therapy (p= .451). **Correlation between Anxiety and rumination** Change in rumination and anxiety symptoms between post- MBT-ASD and 9 months follow-up were significantly correlated (p= 0.024). **MANCOVA** When rumination was added as a covariate, the interaction between time and anxiety for the difference between immediately post-therapy and 9 months follow-up became significant, p= 0.017, ηp^2=0.087).
Kuroda et al. (2022)	State-Trait Anxiety Inventory (STAI Japanese version; Suzuki et al., 2000)	**Group based CBT for Emotional Regulation + Psychoeducation vs Waitlist** **Baseline comparison:** No significant differences in STAI scores between the CBT and WL groups (State: $p = .06$, $d = -.50$; Trait: $p = .10$, $d = -0.43$) **Intervention Period change:** No significant between-group differences (State: $p = .90$, $d = -.04$; Trait: $p = .49$, $d = -.19$) **Study Period change:** No significant between-group differences (State: $p = .38$, $d = .24$; Trait: $p = .80$, $d = .07$)

Oshima et al. (2021)	State-Trait Anxiety Inventory (STAI; Spielberger et al. 1970)	**Comparison between pre-, post-, and follow-up for Schema Therapy (CBT-based)** **rANOVA**: Significant effects of time for STAI-state and -trait (*p*s < .05); however, post-hoc comparison with Bonferroni correction did not remain significant between each time point (alpha = .0007, *p*s not reported, state *d* = .51, 1.08, ,45; trait *d* = .23, .57, .70 respectively for pre-ST vs post-ST, Post-ST vs follow-up, and pre-ST vs follow-up).
Oswald et al. (2018)	ASEBA Adult Self-Report (ASR) (Achenbach & Rescorla, 2003) of DSM-oriented scale for Anxiety Problems	**ACCESS vs Waiting List (ANCOVA)** No significant group difference in change between baseline and post-treatment (*p* = .79, 95% CI = -4.4, -5.8)
Rodgers et al (2018)	Generalized Anxiety Disorder 7 (GAD-7; Spitzer et al., 2006)	**CBT (Pre-intervention vs follow-up)** **Reliable and Clinical Significant Change** One participant recovered (moved from above to below the clinical cut-off, one showed reliable improvement but was already below the clinical cut-off. Two participants showed no change (one remained below the clinical cut-off and one remained above the clinical cut-off
Spain & Blainey (2017)	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) anxiety subscale	**CBT (Baseline vs First session vs Last session vs follow-up)** No difference in anxiety symptoms between baseline and follow-up (means for all timepoints remained above clinical cut-of. Descriptive statistics reported only due to small sample size)
Spek et al. (2013)	The Symptom Checklist-90-revised (SCL-90-R) anxiety subscale (Derogatis, 1994)	**Mindfulness-based Therapy vs Waiting List Control** **MANOVA comparing pre- and post-intervention between groups on 4 outcomes (including anxiety)** Significant main effect of time and Time x Group Interaction (*p* = .003, ηp^2 = 0.35; *p* = .001, ηp^2 = 0.38) **ANOVA for anxiety** Significant main effect of time (*p* < .05 ηp^2 > 0.97) and significant Time by Group interactions: symptoms of anxiety (*p* = .02, ηp^2= 0.12). MBT-AS group showed greater reduction in anxiety symptoms compared to control group based on examination of means (*d* = 0.76 medium effect).

	Correlation with Rumination (The Rumination-Reflection Questionnaire (RRQ, Trapnell & Campbell, 1999) There was a significant correlation between change in rumination and change in anxiety symptoms across groups (p = .005). **MANOVA with change in rumination as a covariate** Time x Group interaction no longer significant for anxiety symptoms (p > .10, ηp^2 = 0.03). However, a test of mediation showed that the indirect effect not significant for depressive symptoms (95% CI = -4.94 to +2.11, p > .10). A test of mediation showed that the indirect effect was significant for anxiety symptoms (95% CI = -3.90 to -0.15), indicating reduction in anxiety could be attributed to reduction in rumination.

Self-Esteem

Three studies reported self-esteem outcomes, including one RCT (Hesselmark et al., 2014) comparing CBT to recreational activities control, and two uncontrolled studies with pre-post design, one using a standalone psychoeducational intervention (Groenendijk et al., 2023) and one using CBT (Spain & Blainey, 2017). All three studies reported using the Rosenberg Self-Esteem Scale (Rosenberg, 1962; 1965). The two CBT studies both reported no significant change from baseline to post-treatment (Hesselmark et al., 2014; Spain & Blainey, 2017), though sample size was small in Spain and Blainey's study (Only 4 participants in the whole study with missing data for 2 participants). The study by Groenendijk et al. (2023) using the standalone psychoeducation intervention found no reliable change for most participants (8 of 9) and only reliable improvement for one participant.

Table 4. Summary of Findings for Studies reporting measures on self-esteem.

Study	Self-esteem Outcome Measure	Summary of Findings
Groenendijk et al. (2023)	Rosenberg Self-Esteem Scale (Rosenberg, 1965)	**Reliable Change Pre to Post Psychoeducation Intervention** No reliable change for eight participants. One participant showed reliable improvement.
Hesselmark et al. (2014)	Rosenberg Self-Esteem Scale (Rosenberg, 1962).	**CBT vs Recreational Activities** No significant difference between pre- and post – treatment for the CBT group (*d* = .21, Mean difference = -1.39 (95% CI = .13, 2.65) No significant difference between pre- and post – treatment for the Recreational Activities group (*d* = -.01, Mean difference = .04 (95% CI = -1.85, 1.76) Between group comparison (*p* =.17)
Spain & Blainey (2017)	Rosenberg self-esteem scale (RSE) (1965)	**CBT (Baseline vs First session vs Last session vs follow-up)** No significant change during intervention, nor at follow-up (descriptive statistics reported only due to small sample size).

Quality of Life

Six studies reported Quality of Life outcomes, including two RCTs, one comparing CBT to Recreational Activities (Hesselmark et al., 2014) and one comparing CBT to Waiting List Control (Kuroda et al., 2022). There were three uncontrolled studies using repeated measure design, including two studies using standalone psychoeducation interventions (Groenendijk et al., 2023; Hidalgo et al., 2022), and one using Schema Therapy (CBT-based; Oshima et al., 2021). There was also one observational study comparing autistic people who received diagnosis-only and those who received both diagnosis and support (including psychoeducation; Beresford et al., 2020).

Four studies (Beresford et al., 2020; Groenendijk et al., 2023; Kuroda et al., 2022; Oshima et al., 2021) used the WHO Quality of Life scale (Skevington et al., 2004; Tazaki & Nakane, 2008; WHO, 2004; WHOQOL Group, 1998), one (Beresford et al., 2020) used the EuroQol-5 Dimensions, five-level version (EQ-5D-5L; EuroQol Group, 1990), one (Hesselmark et al., 2014) used the Quality-of-Life Inventory (Frisch et al., 1992), and one (Hidalgo et al., 2022) used Satisfaction with Life Scale (Diener et al., 1985).

Results from RCTs showed there were no difference between CBT and Waiting List Controls (Kuroda et al., 2022), nor between CBT and Recreational Activities even though quality of life improved across both CBT and Recreational Activities (Hesselmark et al., 2014). An uncontrolled study of Schema based therapy with small sample showed increasing quality of life across time (Oshima et al., 2021), though difference between timepoints not significant after correcting for multiple comparisons. An uncontrolled study of standalone psychoeducation (Hidalgo et al., 2022) with a relatively big sample found significantly improved life satisfaction (small

effect), while another study (Groenendijk et al., 2023) with a small sample found that most participants showed no reliable change or mixed findings on subscales of the WHOQOL. The observation study by Beresford et al. (2020) found no significant improvement for both the Diagnosis-only Group and the Diagnosis & Support at 12 months follow up, though the Diagnosis & Support group showed significant improvement with small effect in psychological quality of life as measured by the WHOQOL at 24 months follow-up, although no significant improvements were found for other WHOQOL quality of life domains or on the EQ-5Q-5L measure.

Table 5.Summary of Findings for Studies reporting measures on Quality of Life.

Study	QoL Outcome Measure	Summary of Findings
Beresford et al. (2020)	The World Health Organization Quality of Life (WHOQOL-BREF; WHO, 2004) psychological domain	**Comparing Diagnosis-Only Group to Diagnosis & Support Group** **Baseline Comparison**. *ns* between Diagnosis-Only and Diagnosis & Support groups (*p* =.17, 95% CI -1.81 to 10.20). **Change over time.** ***Diagnosis and Support Group*.** Time 0 vs Time 3 (12 months), *ns* (*p* = .19, *d* = .12, CI: –4.11 to 0.80) Time 0 vs Time 4 (18 months), *ns* (*p* = *.74, d* =.03) Time 0 vs Time 5 (24 months). Significant improvements from Time 0 to Time 5 (*p* < 0.01, *d* = .34 small effect). ***Diagnosis-Only Group.*** Time 0 vs Time 3, *ns, p* = .12, *d* =.22 **ANCOVA comparing Time 3 outcome between Diagnosis-Only and Diagnosis & Support Group.** *ns* between-groups (*p* = .491).
	WHOQOL-BREF social, physical, and environmental.	**Change over time.** ***Diagnosis & Support group***. Time 0 vs Time 3, *ns*, *p*s > .05, *d*s <.13) Time 0 vs Time 4, *ns*, *ps* > .05 *d*s < .15) Time 0 vs Time 5, *ns*, = *ps* > .05, *d*s <.07) ***Diagnosis-Only group***. Time 0 vs Time 3 =, *ns*, *ps* > .05, *d*s <.173.
	EuroQol-5 Dimensions, five-level version (EQ-5D-5L; EuroQol Group, 1990), Health-related Quality of Life	**Change over time.** ***Diagnosis & Support group***. Time 0 vs Time 3,ns, *p* = .13, *d* = .13 Time 0 vs Time 4, ns, *p* = .81, *d* = .03 Time 0 vs Time 5, *p* = .04, *d* = .11, small effect. ***Diagnosis-Only group***. Time 0 vs Time 3, *p* = 0.724, *d* = .051

Groenendijk et al. (2023)	The World Health Organization Quality of Life (WHOQOL; Skevington et al., 2004) Psychological, Physical, Social, and Environment	**Pre vs Post Psychoeducation for Older adults (multiple case)** **Reliable change using phase end points.** **Psychological.** No change for 7 participants. Reliable improvement for 2 participants **Physical**. No change for 7 participants. Reliable deterioration for 2 participants. **Social.** No change for 3 participants. Reliable improvement for 3 participants. Reliable deterioration for 3 participants. **Environment.** No change for 2 participants. Reliable improvement for 5 participants. Reliable deterioration for 2 participants.
Hesselmark et al. (2014)	The Quality-of-Life Inventory (QOLI; Frisch et al., 1992)	**CBT vs Recreational Activities** **Within-participants effect (across both groups):** Significant improvement from baseline to post-treatment (p = 0.002, d = 0.31, medium effect size) and sustained at follow-up (baseline vs follow-up: p < 0.001, d = 0.39). **Between-group effect**: No difference between CBT (mean difference = .75, 95% CI = .20, 1.29, d = .43) and Recreational Activities (d = .35, mean difference .58, 95% CI = .06, 1.09), p = .19. Replicated in completers-only (between-group effects: p = 0.13)
Hidalgo et al. (2022)	Satisfaction with Life Scale, (SWLS; Diener et al., 1985)	**Pre vs Post Psychoeducation Group Intervention** Improved life satisfaction for participants with ASD (p < .05, d = .14, 95% CI = -.20, -.48, small effect)

Kuroda et al. (2022)	World Health Organization Quality of Life scale (Japanese version of WHOQOL26; Tazaki & Nakane, 2008)	**CBT vs Waitlist.** **Baseline comparison** QOL for CBT > Waiting List (*p* = .01, *d* = .50) **Intervention Period change:** No significant between-group differences (*p* =.53, *d* = .17) **Study Period change:** No significant between-group differences (*p* =.69, *d* = .11)
Oshima et al. (2021)	World Health Organization Quality of Life Brief (WHOQOL-BREF; WHOQOL Group, 1998)	**Comparison between pre-, post-, and follow-up for Schema Therapy (CBT-based)** **rANOVA:** Main effect of time was significant (*p* <.01, increasing trend) but post hoc comparisons between each time point were not significant after Bonferroni correction (alpha = .002 *d* = .69, .21, .92, respectively for pre-ST vs post-ST, Post-ST vs follow-up, and pre-ST vs follow-up

Knowledge of Autism

Four studies reported outcome in relation to knowledge of autism (See Table 6). Two uncontrolled feasibility studies, including one using Cognitive Enhancement Therapy (Eack et al., 2013) and one using a standalone Autism Psychoeducation group intervention (PRISMA; Hidalgo et al., 2022) reported significant improvement from pre-to-post intervention with large effects. One RCT comparing CBT with Recreational Activity (Hesselmark et al., 2014) found CBT to be superior at follow-up, whereas another RCT (Kuroda et al., 2022) comparing CBT and waitlist control found no differences in change between pre- and post-intervention periods. All four studies used unvalidated measures to assess knowledge of autism designed specifically for their study purpose, with two assessing objective knowledge using quiz like measures (Hidalgo et al., 2022; Kuroda et al., 2022) and two reporting subjective knowledge (Eack et al., 2013; Hesselmark et al., 2014). The inconsistent findings are therefore likely to have been influenced by variation of outcome measurement properties and study design, such as whether a comparison group is used and what type.

Table 6. Summary of Findings for Studies reporting measures on Knowledge of Autism.

Study	Knowledge of Autism Outcome Measure	Summary of Findings
Eack et al. (2013)	Knowledge of autism and adjustment to disability were assessed as part of the Cognitive Style and Social Cognition Eligibility Interview (based on Hogarty et al., 2004, but adapted for ASD)	**Baseline vs post-treatment (at the end of 18 months Cognitive Enhancement Therapy:** Significant improvement in participants' ability to adjust to their condition (p<.001, d = -1.82, large effect)
Hesselmark et al. (2014)	Rating on a statement "I have a greater understanding of my own difficulties" using 5-point Likert scale ('strongly agree' to 'disagree'. No neutral option.). Dichotomized responses into 'agree' and 'disagree'.	**CBT vs Recreational Activities at follow-up** 76% of ALL participants reported improved understanding. Significantly higher rates of positive responses for CBT compared to Recreational Activities (p < 0.05) at post-36-weeks treatment follow-up.
Hidalgo et al. (2022)	ASD 20 Questions (knowledge quiz) measuring acquired knowledge of ASD and support and services with true/false/I don't know options. (Internal consistency based on baseline data reported)	**Pre vs Post Psychoeducation group intervention** Acquired knowledge of ASD increased from pre- to post-intervention (p < 0.001, d = 0.96 large effect, 95% CI: 0.59–1.31)
Kuroda et al. (2022)	Study specific ASD-Q self-report questionnaire to assess *knowledge* and attitudes regarding ASD, including 5 knowledge questions (1 = true to 3 = not true).	**CBT vs Waitlist** **Baseline Comparison** No significant differences in ASD-Q knowledge scores between CBT and WL groups (p = .60, d=.21) **Intervention Period (8 weeks) Change (Independent t-test)** No significant between-group differences in intervention period changes in the ASD-Q knowledge scores (p = .42, d = 0.21) **Study Period Change (16 weeks follow-up)** No significant between-group differences (p =.88, d = .04)

Acceptance of Diagnosis

Only two studies reported outcomes relating to acceptance (see Table 7), these included an RCT comparing CBT with recreational activities (Hesselmark et al., 2014) and an uncontrolled feasibility study of a standalone psychoeducation group intervention (Hidalgo et al., 2022). Using an unvalidated one item measure, Hesselmark et al. found no difference between CBT and reactional activities at follow-up; whereas Hidalgo et al. found acceptance at post-intervention significantly increased from baseline with small effect using an adapted acceptance measure with satisfactory psychometric properties (Bond et al., 2011).

Table 7. Summary of Findings for Studies reporting measures on Acceptance of Diagnosis.

Study	Acceptance of Diagnosis Outcome Measure	Summary of Findings
Hesselmark et al. (2014)	Rating on a statement “my self-acceptance has improved” using 5-point Likert scale (‘strongly agree’ to ‘disagree’) No neutral option.). Dichotomized responses into ‘agree’ and ‘disagree’.	62% of participants reported improved self-acceptance. **CBT vs Recreational Activities at follow-up** no differences between group. (p =0.12)
Hidalgo et al. (2022)	adapted version of the Acceptance and Action Questionnaire-II (Bond et al., 2011) “What I think about my diagnosis” for adults with ASD	**Pre vs Post Psychoeducation group intervention** Participants with ASD reported slightly increased acceptance of their diagnosis (p<.05, d = 0.15 (95% CI: -0.20–0.49)

Quality Appraisal

Percentage of agreement between raters was 81.4%. Quality ratings for all articles are presented in Table 8. Summary scores ranged from .455 to .875 with a mean of .680 (*SD* = .128). In general, RCTs (Ashman et al., 2017; Hesselmark et al., 2014; Kuroda et al., 2022; Spek et al., 2013; Oswald et al., 2018; Smith DaWalt et al., 2021; White et al., 2016) tend to score higher on quality (*M* = .731, *SD* = .120, Range = .500 to .875) compared non-RCTs (*M* = .651, *SD* = .128, Range = .455 to .818) (Beresford et al., 2020; Eack et al., 2013; Groenendijk et al., 2023; Helverschou et al., 2019; Hidalgo et al., 2022; Howlin & Yates, 1999; Kiep et al., 2014; Krämer et al., 2021; McDonald e al., 2023; Oshima et al., 2021; Pugliese & White, 2014; Spain & Blainey, 2017). Whilst the current review did not exclude study based of quality, four studies including three non-RCTs (Helverschou et al., 2019; Howlin & Yates, 1999; Pugliese & White, 2014) and one RCT (White et al., 2016) would have met the lowest recommended cut-off score of .55 (Kmet et al., 2004), indicating relatively low quality. All four received a score of 0 for Item 9 indicating inadequate sample sizes. Only three studies were considered to have sufficient sample size (Hidalgo et al., 2022 Kiep et al., 2014, McDonald et al. 2023); all three used repeated measure design and differed in the type of intervention used (Standalone Psychoeducation: Hidalgo et al., 2022 Mindfulness-based Therapy: Kiep et al., 2014; Multi-component intervention; McDonald et al., 2023) (See Item 9 of Table 8).

Blinding of investigators and participants were not possible for most of the studies described in this review given the nature of interventions requiring investigators to deliver the therapy and psychoeducational intervention and participants being aware of the content of the interventions (See Item 6 and 7 of

Table 8). For the seven RCTs, three adequately described randomisation (Ashman et al., 2017; Kuroda et al., 2022; Spek et al., 2013), whereas four did not sufficiently report method of randomisation (Oswald et al., 2018; Smith DaWalt et al., 2021; White et al., 2016) or introduced participants into the control group after randomisation occurred (Hesselmark et al., 2014), which could have introduced bias due to untrue randomisation (See Item 5 of Table 8).

In terms of participant selection, whilst the included studies generally did not show obvious inappropriateness, most received "partial" scores due to not fully describing how participants were selected, for example, if participants were recruited from service, it was often unclear whether all participants were invited to take part or handpicked by clinicians (see Item 3 of Table 8). Only three study received full score for this item (Beresford et al., 2020; Krämer et al., 2021; McDonald et al., 2023). Only 6 studies appropriately controlled for confound which included 4 RCTs (Ashman et al, 2017; Oswald et al., 2018; Smith DaWalt et al., 2021; Spek et al., 2013), one observational study (Beresford et al., 2020), and a follow-up study (Kiep et al., 2014). For the studies that received an imperfect score for Controlling for Confound (Item 9), the most common reason was not having a control group to account for practice/placebo effect. Over half of the studies received partial scores due to using unvalidated outcome measures (e.g. measures for Knowledge of Autism and Acceptance as reported above) which could have increased risk of measurement bias. Half of the studies received partial scores for Item 10 and Item 13 for not sufficiently describing analytic methods and results. In general, studies fared well on describing objectives (Item 1), evidencing and using appropriate study design (Item 2), and sufficiently describing participant group characteristics (Item 4), reporting variance estimates (Item 11), and providing conclusions that are supported

by the result (Item 14), with over half of the studies receiving full score for these items.

Table 8. QualSyst Quality Appraisal Ratings for Included Quantitative Studies

Author (Year)	1 Question / objective sufficiently described?	2 Study design evident and appropriate?	3 Method of subject/comparison group selection or source of information/input variables described and appropriate?	4 Subject (and comparison group, if applicable) characteristics sufficiently described?	5 If random allocation to treatment group was possible, was it described?	6 If interventional and blinding of investigators was possible, was it reported?	7 If interventional and blinding of subjects was possible, was it reported?	8 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement /misclassification bias? Means of assessment reported?	9 Sample size appropriate?	10 Analytic methods described/justified and appropriate?	11 Some estimate of variance is reported for the main results?	12 Controlled for confounding?	13 Results reported in sufficient detail?	14 Conclusions supported by the results?	summary score
Ashman et al. (2017)	Yes	Yes	Partial	Yes	Yes	N/A	N/A	Yes	Partial	Yes	Partial	Yes	Yes	Yes	.875
Beresford et al. (2020)	Partial	Partial	Yes	Partial	N/A	N/A	N/A	Yes	No	Yes	Yes	Yes	Yes	Yes	.773
Eack et al. (2013)	Yes	Partial	Partial	Yes	N/A	N/A	N/A	Partial	Partial	Yes	Yes	No	Yes	Partial	.682
Groenendijk et al. (2023)	Yes	Partial	Partial	Partial	N/A	N/A	N/A	Partial	No	Partial	Yes	Partial	Partial	Yes	.591
Helverschou et al. (2019)	Partial	Partial	Partial	Yes	N/A	N/A	N/A	Yes	No	No	Partial	No	Partial	Partial	.455
Hesselmark et al. (2014)	Yes	Yes	Partial	Yes	Partial	N/A	N/A	Partial	Partial	Yes	Yes	Partial	Partial	Yes	.750
Hidalgo et al. (2022)	Partial	Yes	Partial	Yes	N/A	N/A	N/A	Partial	Yes	Yes	Yes	Partial	Yes	Partial	.773
Howlin & Yates (1999)	Partial	Partial	Partial	Partial	N/A	N/A	N/A	No	No	Partial	Yes	No	Partial	Yes	.455
Kiep et al. (2014)	Yes	Partial	Partial	Partial	N/A	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Partial	Yes	.818
Krämer et al. (2021)	Partial	Partial	Yes	Yes	N/A	N/A	N/A	Yes	Partial	Yes	Yes	No	Yes	Yes	.773

Author (Year)	1 Question / objective sufficiently described?	2 Study design evident and appropriate?	3 Method of subject/comparison group selection or source of information/input variables described and appropriate?	4 Subject (and comparison group, if applicable) characteristics sufficiently described?	5 If random allocation to treatment group was possible, was it described?	6 If interventional and blinding of investigators was possible, was it reported?	7 If interventional and blinding of subjects was possible, was it reported?	8 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement /misclassification bias? Means of assessment reported?	9 Sample size appropriate?	10 Analytic methods described/justified and appropriate?	11 Some estimate of variance is reported for the main results?	12 Controlled for confounding?	13 Results reported in sufficient detail?	14 Conclusions supported by the results?	summary score
Kuroda et al. (2022)	yes	yes	partial	Yes	Yes	Yes	N/A	Partial	Partial	Partial	Yes	Partial	Partial	Yes	.769
McDonalde et al. (2023)	Partial	Partial	Yes	Yes	N/A	N/A	N/A	Partial	Yes	Partial	Yes	Partial	Yes	Partial	.727
Oshima et al. (2021)	yes	yes	Partial	yes	N/A	N/A	N/A	yes	Partial	yes	Partial	No	Partial	yes	.727
Oswald et al. (2018)	Yes	Yes	Partial	Yes	Partial	N/A	N/A	Partial	Partial	Yes	Yes	Yes	No	Yes	.750
Pugliese & White (2014)	Partial	Yes	Partial	Partial	N/A	N/A	N/A	Partial	No	Partial	No	Partial	Yes	Partial	.500
Rodgers et al. (2018)	Partial	Yes	Partial	Partial	N/A	N/A	N/A	Partial	N/A	Partial	N/A	N/A	No	Yes	.563
Smith DaWalt et al. (2021)	Yes	Yes	Partial	Partial	Partial	N/A	N/A	Partial	Partial	Partial	Yes	Yes	Partial	Partial	.667
Spain & Blainey (2017)	yes	Yes	Partial	Partial	N/A	N/A	N/A	Yes	No	Partial	Yes	No	Yes	Partial	.636
Spek et al. (2013)	yes	yes	Partial	Yes	Yes	Partial	N/A	Yes	Partial	Partial	Yes	Yes	Partial	Yes	.808
White et al. (2016)	Partial	Partial	Partial	Partial	Partial	Yes	N/A	Partial	No	Partial	partial	Partial	Partial	Partial	.500

Note. Summary scores were calculated using formula provided in Kmet et al.(2004, p.14). Summary scores = total sum / total possible sum. Total sum = (number of "yes" * 2) + (number of "partials" * 1). Total possible sum = 28 – (number of "N/A" * 2).

Discussion

The aim of the current review was to gain an understanding of whether autism psychoeducation interventions could improve mental health outcomes for autistic adults. Review of the included studies suggested that autism psychoeducation may have a positive effect on depression, anxiety, quality of life, acceptance, and knowledge of autism, but no effect on self-esteem. However, the evidence for these findings is weak overall. The results will be discussed here in the context of the extant literature. The limitations of the included studies and the current review will also be discussed.

Cognitive behavioural theories would suggest that one way autism psychoeducation may work to reduce depression and anxiety could be through cognitive restructuring of negative automatic thoughts and core beliefs about one's longstanding struggles (Beck et al., 2021). Furthermore, autism psychoeducation may encourage autistic people to think about the strengths that being autistic brings for them. These changes in cognition could then positively influence emotional response, leading to a reduction in depression and anxiety. Though note that the positive effects of CBT (combined with psychoeducation) and standalone psychoeducation are mainly only supported by small scale and uncontrolled studies in this review (Hidalgo et al., 2022; Rodgers et al., 2018; Spain & Blainey, 2017; Oshima et al., 2021).

Thinking differently about their experiences in the lens of autism may also help autistic people increase acceptance for their differences. Increase in self-acceptance through autism psychoeducation could encourage behavioural changes in autistic people, for example, by better management of sensory environment and reducing masking behaviours, which may then have a positive impact on quality of

life in the long-term. Indeed, our review found that some positive effects of psychoeducation interventions on quality of life, though again these were mostly based on uncontrolled studies (Beresford et al., 2020, Hidalgo et al. 2022; Oshima et al., 2021).

Recent research had suggested that time spent camouflaging is linked to exhaustion and poor mental health and loss of self-acceptance in autistic adults (Bradley et al., 2021). An intervention that focussed on altering an autistic person's way of understanding and relating to others through masking therefore puts undue pressure on the autistic people to conform to neurotypical norms, which could be detrimental to autistic people's mental health. This potential negative association between masking and mental health may explain why mentalisation therapy led to worsening of depression with medium effect, though note that this hypothesis is based on one study in our review (Kramer et al., 2021) combining mentalisation therapy with psychoeducation and requires further investigation.

The small number of studies that reported self-esteem as an outcome measure did not show any effects of psychoeducation interventions on self-esteem. A possible explanation for this could be that it is a false negative finding due to small sample sizes of the available studies. Another possibility could be because self-esteem tends to be stable across time and resistance to change through several maintenance processes, including repeated exposure to esteem-threatening situations, such as social rejection, and the propensity to accept negative feedback rather positive feedback (Creswell et al., 2019; Joseph et al., 2003). Alternatively, it could be that the lack of change in self-esteem across studies was linked to the content of the psychoeducation.

Cooper et al., (2017) suggested that developing a positive autism identity may offer protection against poor mental health through increase in personal and collective self-esteem. Therefore, it is possible that psychoeducation that is strength based or focussed on fostering a positive autism identity is more beneficial for improving self-esteem compared to a deficit-based approach. An argument against a fully strength focussed approach though, is that it could potentially undermine the struggles autistic people face, and that some sensitive discussions validating common difficulties and individual differences in support needs could equally be beneficial.

Findings from randomised trials for depression and anxiety largely mirrored one another, with small number of available RCTs showing a lack of effect of CBT combined with psychoeducation but positive effect for mindfulness-based therapy (Hesselmark et al., 2013; Kuroda et al., 2022; Spek et al, 2013; Kiep et al., 2014), which is perhaps unsurprising given the high co-occurrence of the two conditions and shared psychological processes (Kalin, 2020). Recent systematic reviews and meta-analysis (Forbes & Miller, 2023; Wichers et al., 2023) on the effects of mindfulness stress-reduction and CBT interventions on autistic adults (not necessarily including autism psychoeducation) found that both types of interventions led to reduction in anxiety and depression, though high risk of publication bias were found. It is unknown how much of improvements in mental health outcomes in the current autistic sample were attributable to effects of the autism psychoeducation components or other psychological components such as CBT and Mindfulness that were incorporated within the interventions. Within the NHS, autism psychoeducation is often offered (if any) as part of post-diagnostic care of the adult autism diagnostic pathway, whereas therapeutic support for autistic people is offered within

mainstream mental health services. It remains to be tested whether these interventions are best delivered in conjunction or separately.

One potential confound for the positive effects of psychoeducation interventions is the effect of socialisation. Majority of studies within this review utilised group format or social elements where autistic people had the opportunity to interact with each other (Ashman et al., 2017; Eack et al., 2013; Groenendijk et al., 2023; Hesselmark et al., 2014; Hidalgo et al., 2022; Howlin & Yates, 1999; Kiep et al., 2014; Krämer et al.,2021; Kuroda et al., 2022; McDonald et al., 2023; Oswald et al., 2018; Pugliese & White, 2014; Smith DaWalt et al., 2021; Spain & Blainey, 2017; Spek et al., 2013; White et al., 2014). Interestingly, Hesselmark et al. (2014) found that, both their treatment group (CBT and psychoeducation combined) and their active control group (recreational activities) both experienced increased in acceptance and quality of life, with no superiority found for the treatment group. It is therefore possible that group-based interventions were improving these outcomes indirectly through increased social support. This hypothesis is supported by findings by Mason et al. (2018), who found associations receiving support is positively associated with quality of life. Positive social interactions, such as opportunities to share experiences with other autistic people, and having autistic people's involvement in the creation and delivery, may be important elements to be considered when designing psychoeducation intervention, and may promote acceptance of one's condition. On the other hand, it is also crucial to consider autistic people's individual preferences, needs and characteristics, such as experience of social anxiety, in whether group type interventions are appropriate.

Limitations of the included studies

The quality appraisal indicated that studies evaluating psychoeducation interventions were generally problematic in several ways. Most studies were non-randomised, without a control group, and have small sample sizes, and did not appropriately control for these confounds. Within the small number of randomised studies, blinding was not possible due to the nature of the interventions. Furthermore, over half of the studies used some type of unvalidated outcome measures. While studies generally used validated measures for well-established psychological constructs such as depression, anxiety, quality of life, and self-esteem, there is a lack of validated measures for two of the target outcomes of this review, namely, knowledge and acceptance of autism. The use of unvalidated measures in the included studies meant that results for knowledge and acceptance are prone to measurement bias and should be interpreted with caution. For the measure of knowledge of autism, it remains a question as to whether subjective (perceived) or objective knowledge of autism is the more important outcome for autistic people.

Content of psychoeducation within the included studies were generally under-reported and materials are usually not publicly available. Furthermore, most studies within the review do not explicitly conceptualise whether strength or deficit-based approaches were used, making it difficult to assess and compare the effects of the different approaches on autistic people's mental health. It remains to be tested whether strength-based approaches (e.g., Lee et al, 2023; Taylor et al., 2023) would lead to more positive outcomes compared to deficit-based approaches. Our review also found that the studies on psychoeducation were highly heterogenous in nature. These differences included whether randomisation was used and whether control group were used and what type. In additional, the type of interventions varied greatly, including both standalone psychoeducational interventions and

psychoeducation combined with other types of psychotherapy or treatment. It is impossible to know whether any effects from combined interventions were attributable to the psychoeducational component or other treatment components.

Very few studies involved autistic people in the design and delivery of the interventions. Involving the autistic community in co-producing research could improve the design, feasibility, ethical integrity of the intervention and maximise benefits of the interventions for autistic people (Gowen et al., 2019).

Limitations of the current review

The current review had several limitations. Only a selection of psychological outcomes was reported within this review as there are currently no standardised core outcome set for evaluating autism psychoeducation interventions. However, effort has been made to select the most relevant outcome measures in line with autism community priorities (James Lind Alliance, 2016), expected treatment targets for autism psychoeducation (Beresford & Mukherjee, 2023), and commonly evaluated mental health outcomes in autism and the general population (Au-Yeung et al., 2019; Cooper et al., 2017; Mason et al., 2018) No meta-analyses were conducted due to the designs of the included studies varying greatly and combining studies across different design is generally not recommended due to increased heterogeneity and risk of bias (Reeves et al., 2023). The final search criteria deviated from the original PROSPERO protocol, however, this was necessary due to low returns of relevant articles using the original strategy. The updated criteria allowed a more exhaustive search of the literature. While qualitative findings are not available in this report, autistic people's subjective experiences of psychoeducation interventions would be a helpful source of information for improving the design and delivery of future interventions.

Clinical Implications and Future Directions

Currently, a more robust evidence base is required before definitive conclusions on effectiveness on the selected outcome measures can be concluded. Replication of the studies examining the effects of psychoeducation on mental health outcomes with appropriate comparison group, sample size, and power calculation are required. Future studies should also consider comparing the effects of combined psychotherapy and psychoeducation intervention versus psychoeducation alone interventions. Researchers and Clinicians should consider making available service evaluation findings for any routine psychoeducation interventions and making psychoeducation materials publicly available for evaluation purpose. Researchers may consider developing a core outcome set relevant for autism psychoeducation which will allow the effectiveness of autism psychoeducation interventions to be systematically evaluated. Both researchers and clinical services should also consider involving autistic people in the design and delivery of post-diagnostic psychoeducation interventions.

Conclusions

In conclusion, this review found that there are 20 quantitative studies evaluating interventions including a psychoeducation component for autistic people without an intellectual disability; three studies used standalone autism psychoeducation and 17 studies combined autism psychoeducation with other types of interventions. When used alone or in combination with common psychotherapeutic approaches such as CBT or Mindfulness based therapy, autism psychoeducation may have positive effects on the mental health of autistic adults with potential to reduce depression and anxiety, and improve quality of Life through increased self-acceptance, development of positive autism identity, and increase social

connectedness. However, it is important to note that studies varied greatly on study designs, with most being non-randomised studies, had small samples, and inconsistent findings probably due to insufficient statistical power. Only a minority of studies reported self-esteem, knowledge, and acceptance of autism diagnosis, the preliminarily conclusions from which showed a lack of effect of the interventions on self-esteem, but some positive effects on knowledge and acceptance. There is, however, a lack of validated measures for knowledge and acceptance, and a lack of agreement of how knowledge should be classified.

Contributions

S-AY and MF were involved with developing the idea for the systematic review. S-AY wrote the study protocol and MF, DP, and LP provided valuable feedback to improving the study protocol. S-AY and SC were involved in the title and abstract screening process. S-AY reviewed all articles at the full-text stage and completed the quality appraisal. MF and DP supported consensus for the full-text stage and quality appraisal. The final report was produced by S-AY.

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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.	p.1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p. 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p. 5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.6
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p.10, p.25
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.	p.8-11
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix B
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.	P.10-11
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.	p.11-12
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.	p. 25
	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.	p.17-24
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.	p.12
Effect	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	p.11-12

Section and Topic	Item #	Checklist item	Location where item is reported
measures			
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)).	p.11-12
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	p.11-12
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p.11-12
	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.	p.11-12
	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.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	p.12
Certainty assessment	/A	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	p.12
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.	p.14
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p.13
Study characteristics	17	Cite each included study and present its characteristics.	17-24
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p.47-51
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.	p.15-24
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p.25-51
	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
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	p.25-51
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	p.47-51
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	p.47-51
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p.53-57
	23b	Discuss any limitations of the evidence included in the review.	p.53-57
	23c	Discuss any limitations of the review processes used.	p.53-57
	23d	Discuss implications of the results for practice, policy, and future research.	p.57-58
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.	p.2, p.8
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p.8
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	p.8-9
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	p.2
Competing interests	26	Declare any competing interests of review authors.	p.58
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.	p.58

Appendix B

Search Strategy

Ovid-SP (PsychInfo and Medline)

Year: 1946 to May 18, 2023

Ovid MEDLINE(R) ALL <1946 to May 18, 2023>
APA PsycInfo <1806 to May Week 2 2023>

1 (Autis* or Asperger* or Pervasive developmental disorder*).ti,ab.
2 (Adult* or Men or Man or Women or Woman).ti,ab.
3 (psychoeducation* or psycho-education* or program* or intervention* or support*).ti,ab.
4 1 and 2 and 3

Result = 7127 records

SCOPUS

TITLE-ABS ((autis* OR asperger* OR "Pervasive developmental disorder*") AND (adult* OR men OR man OR women OR woman) AND (psychoeducation* OR psycho-education* OR program* OR intervention* OR support*))

Result: 4592 records

Web of Science

(AB=((Autis* OR Asperger* OR "Pervasive developmental disorder*") AND (Adult* OR Men OR Man OR Women OR Woman) AND (psychoeducation* OR psycho-education* OR program* OR intervention* OR support*)))

Results = 4383 records

(TI=((Autis* OR Asperger* OR "Pervasive developmental disorder*") AND (Adult* OR Men OR Man OR Women OR Woman) AND (psychoeducation* OR psycho-education* OR program* OR intervention* OR support*)))

Results= 351 records

CINAHL

Limiters/Expanders: Expanders - Apply equivalent subjects
Search modes - Boolean/Phrase

Last Run Via: Interface - EBSCOhost Research Databases
Search Screen - Advanced Search
Database – CINAHL

AB (Autis* OR Asperger* OR "Pervasive developmental disorder*") AND AB(Adult* OR Men OR Man OR Women OR Woman) AND AB (psychoeducation* OR psycho-education* OR program* OR intervention* OR support*)

Results = 1602 records

TI (Autis* OR Asperger* OR "Pervasive developmental disorder*") AND TI (Adult* OR Men OR Man OR Women OR Woman) AND TI (psychoeducation* OR psycho-education* OR program* OR intervention* OR support*)

Results = 198 records

Result = 1667

_____

Total from all databases from search = 18120 records

Appendix C

R Script used for selecting 20% of articles for quality appraisal consensus

```
library(readxl)
library(tidyverse)
Included_Full_text_Articles <- read_excel("Included Full-text Articles.xlsx")

#whats 20% of the record
percent <- round(nrow(Included_Full_text_Articles) * 0.20, digits = 0)

set.seed(10)
#selects the random sample to review
qual_assesment <- Included_Full_text_Articles %>%
  sample_n(percent)

write.csv(qual_assesment, "manuscripts_quality_assessment.csv")
```

Chapter Two

Qualitative Study on Autistic Adult's Experiences of Diagnostic Disclosure Using Interpretative Phenomenological Analysis

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Research Supervisor

Prof Megan Freeth

Collaborator:

Prof Andrew Thompson (University of Cardiff)

Abstract

Background

Increasing number of people are receiving diagnosis of autism in adulthood and there are very few studies exploring autistic people's experiences of disclosing their diagnosis in adulthood. This study therefore aims to explore autistic adults' experiences disclosure in UK within the last 10 years.

Method

Twelve autistic adults took part in semi-structured interviews exploring their experiences of disclosing their diagnosis. Interpretative Phenomenological Analysis was used to analyse the data.

Results

Six group experiential themes emerged: "Functions of Disclosure" (Accessing Support; Becoming Myself; Activism and its Burden); "Approaching the Conversation (Managing Disclosure and Responses; Disclosure Started Pre-Diagnosis); "Negative Effects of Preconceptions" (Disbelief; Imposter Syndrome; Not Having My Needs Met; Caution and Avoidance), "Impact on Others", "Positive Aspects of Disclosure" (Acceptance and Understanding; Finding Community), and "Need for Support for Considering how to Disclose and Handling Reactions".

Conclusions

Autistic people can have different reasons for disclosing their diagnosis; these could be for practical, personal, or altruistic reasons. Autistic people found that disclosure is a balancing act and require consideration of how much information to disclosure as well as the feelings and reactions of others. While disclosure could bring positive experiences such a sense of acceptance and community for autistic people, negative experiences

associated with people preconceptions of autism could also be emotionally challenging for autistic people and prevent autistic people from having their needs met. Autistic people varied greatly on the support they received around disclosure and more consistent post-diagnostic support is required.

Practitioner Points

- Clinicians should include incorporate discussion routine post-diagnostic support sessions
- Clinicians may wish to consider the risks and benefit of disclosure with newly autistic people across different context, including the potential for increased support and understanding, as well as the potential for misunderstanding and discrimination.
- Clinician may wish to consider the different strategy for disclosures with autistic people, such as how much information to disclosure and the best way to disclose.
- Clinicians may wish to discuss with autistic adults potential reactions from others and how to handle these reaction, and allow space for autistic adult to process the effect of these responses on the autistic person.

Key Words: Autism, Adults, Disclosure, Qualitative, Interpretative Phenomenological Analysis

Introduction

After going through a diagnostic process and receiving an autism diagnosis, autistic people may choose to share their diagnosis with others. As discussed in the previous chapter, there is a lack of clear and detailed guidance on what post-diagnostic care should look like for autistic adults. While NICE (2012) advise clinicians to talk to the newly diagnosed person about the implications and concerns about the diagnosis and any future support needs, there is no advice about *how* clinicians should go about engaging autistic people on conversations regarding disclosure. Accessing support post-diagnosis, such as reasonable adjustments for disabilities under the Equality Act (2010), often requires an individual to disclose details of their diagnosis to those around them, such as employers, educators, and health professionals. It is therefore not only important that autistic people are receiving timely diagnosis (Rutherford et al., 2016), but also to be engaged in conversation around disclosure, and if in line with their wishes, to be supported to effectively communicate their diagnosis to others in a way that is helpful and acceptable to autistic people.

A systematic review by Lindsay et al. (2021) explored disclosure and workplace accommodations for autistic people and found 26 studies completed in Western countries, with only one in the UK (Richards, 2012). Very few studies in the review examined disclosure directly, however, both pros and cons of disclosing an autism diagnosis in the workplace were noted. The benefits included greater acceptance and inclusion within the workplace and receiving accommodations during the recruitment process and at work. Accommodations ranged from adaptations in working patterns, environment, responsibilities, support with social communication, and increased autism awareness amongst colleagues. Negative outcomes of disclosure included experiences of stigma and discrimination, such as not getting hired in the first place (Nicolas et al., 2018, but see Ohl et al., 2017). Lindsay et al. also found that the decision to disclose may be influenced by

several factors, including the age of diagnosis, with those diagnosed earlier perceiving less discrimination after disclosure, social demand of job, and workplace policies (Johnson & Joshi, 2016).

Huang et al. (2022) completed a mixed method survey study in Australia investigating autistic adults' decision-making for disclosure and nondisclosure across different contexts. Using content analysis, they found reasons to disclose included 1. wanting to help others understand them and to seek support, particularly in situations where their autism may interfere with relationships and work demands; 2. to raise public awareness of autism; 3. to express their identity. Reasons for nondisclosure included avoiding anticipated misunderstandings and prejudice, lack of relevance, and not wanting to be labelled. In considering disclosure, autistic people often must make choices about protecting themselves and activism (Davidson & Henderson, 2010). In line with Lindsay et al.'s (2021) review, Huang et al. (2022) also found that there were both positive and negative consequences of disclosure. Positives included increased understanding and acceptance, receiving professional or social support, and improved relationships, while the negatives included being dismissed, judged, misunderstood, and being doubted due to the autistic person's apparent capabilities. Negative experiences of disclosure may not only create unnecessary stress for autistic people, but could also subsequently affect future decisions to disclose, leading to withdrawing from or losing out of important support that they need (Dugdale et al., 2021).

While the study by Huang et al. (2022) provided some direct insight into experience of autism disclosure, the study sample included autistic people who received their diagnosis across both childhood and adulthood, therefore it was not possible to identify the specific challenges experienced by those diagnosed in adulthood. Timing of finding out about one's diagnosis may also affect how a person views their diagnosis as people diagnosis earlier in life are likely to less autonomy over whether a diagnosis was sought out (Huws &

Jones, 2008). Hence, there is a need to consider similarity and differences of experiences of autistic people diagnosed in childhood and those diagnosed in adulthood.

A recent evaluation of an autism-led post-identification programme (Crane et al., 2021) found that, exploration of issues around disclosure in different context and provision of practical support to consider who to disclose to and how, was valued by participants and helped them develop a positive outlook on being autistic. Similarly, a recent Delphi study (Crowson et al., 2023) showed that autistic adults would like practical support to help them disclose their diagnosis to others in their personal life and at work when they feel ready. Given the limited national guidance on what post-diagnostic support should look like and the growing interests on the importance of including considerations of diagnostic disclosure as part of post-diagnostic support, a study to identify clear recommendations in this area is required for professionals, including clinical psychologists, to support autistic adults to make informed decisions about disclosure and accessing support.

Aims

The aim of the proposed study is to explore how autistic adults in the UK experience the process of disclosing their autism diagnosis to others. We are interested in the context around disclosures and non-disclosure (e.g. who, where, why, how, etc), how autistic people make sense of their experiences of disclosure (e.g. thoughts/feelings) and the effects these experiences have on them. We are also interested in the considerations surrounding the decision to disclose or not disclose; how experiences are different or similar across contexts; and how participants' previous experiences impact later disclosures. Finally, we are also interested how participants experienced support around disclosure, if any, and what they would find useful.

Methods

Design

Interpretative phenomenological analysis (IPA, Smith et al., 2021) was used to explore autistic adults' experiences of disclosure and semi-structured interviews were conducted individually with autistic people who received their diagnosis in adulthood to allow the researcher to gain in-depth first-person account of autistic people's experiences. The IPA approach allows open-ended responses from participants to be analysed in a way that allows researchers to engage in a double hermeneutic process to make sense of participants' making sense of their own experiences. It also allows the identification of similarities and nuances in a particular phenomenon (diagnostic disclosure) experienced by a specific group (autistic people diagnosed in adulthood) within a given context (diagnosed in the UK in the last 10 years).

Consultation

Two autistic adults were consulted regarding the interview questions (Appendix A) to ensure that questions are worded clearly and sensitively, and to ensure that the content of the interview are important and relevant to autistic people's experiences. Feedback on participant facing documents, including the participant information sheet, and debriefing statement, were also sought to ensure that these were clear and sensitive. Consultations were conducted using each individual's preferred method. One person provided feedback over email and one provided feedback via an online meeting. The interview guide was then further amended, and an updated version was shared with the project supervisor and autistic adults involved in the consultation for final comments. Autistic adults were compensated with a £25 shopping voucher.

Participants

Participants were 12 autistic adults (aged 18 years or over) recruited purposively through two methods. Firstly, email invites including a Participant Information Sheet (Appendix B) were sent to potential participants within the Sheffield Autism Research Lab (ShARL) database who have consented to be contacted about research studies they are

potentially eligible for. Secondly, advertisements were posted on Facebook and ShARL website (Appendix C). Online ads and PIS stated the inclusion criteria (Table 1) and potential participants contacted the researcher by email if they wanted to participate. Participants' characteristics are summarised in Table 2.

Table 1. Inclusion Criteria and Justification.

Inclusion Criteria	Justification
has a formal diagnosis of Autism. Diagnostic variants could include Aspergers Syndrome, Autistic Disorder, high-functioning autism, Autism Spectrum Disorder, Autism Spectrum Conditions, Pervasive Developmental Disorder etc.	The broad definition of Autism was used given that autistic people diagnosed in the last 10 years are likely to have received a range of different diagnoses. This could be due to the changes in diagnostic categories in both the DSM-V (APA, 2013) and ICD-11 (World Health Organisation, 2019) in the recent decade which eliminated subtypes categorisation such as Asperger's Syndrome, Autistic Disorder and Pervasive Developmental Disorder. However, given the recency of these changes and the lack of consensus and consistency in the categories and diagnostic manual used across adult autism diagnostic services in the UK, these different labels under the umbrella of Autism could still have been used for formal diagnosis.
received a diagnosis as an adult	Autistic people diagnosed as adults are likely to have very different experience of disclosure compared to those diagnosed as children, as the former are likely to have spent more time masking their differences (Bradley et al., 2021) and used compensatory strategies to fit in socially (Livingston et al., 2020), therefore it may come as more of a surprise for those being disclosed to and may therefore respond differently to the autistic person disclosing their diagnosis (Huang et al., 2020). To capture these unique experiences, only those diagnosed as an adult were included in the study.
received the diagnosis within the last 10 years in the UK	Experience of diagnostic disclosure are likely to be influenced by political changes such as instilling of government legislation such as the Equality Act (2010) and Autism Act (2009). Therefore, to capture the specific experience of autistic people within the influence of a similar system context, only those who received a diagnosis within the last 10 years in the UK were included.
living in the UK	This was to allow safeguarding of participants, risk management, and allow the signposting of participants to local/national support services if required as part of the debriefing process.

Table 2. Participant Characteristics

Participant Pseudonym	Gender	Age	Age of Diagnosis	Ethnicity	Diagnosis received	Type of diagnostic service	Other Neurodevelopmental Diagnosis
Helen	Female	34	34	White British	Autism Spectrum Disorder	NHS	ADHD - combined type
Josh	Male	30	30	White British	Autism Spectrum Disorder	NHS	None
Olivia	Non-binary	28	26	Mixed British and South Asian	Autism Spectrum Disorder	NHS	None
Jane	Female	51	48	White British	High Functioning Autism	NHS	None
Michael	Male	49	42	White British	Asperger's Syndrome	NHS	None
Eric	Non-binary	49	41	White Irish (Northern Irish/British)	Asperger's Syndrome	Private	None
Tina	Female	61	56	White British	Autism Spectrum Disorder	NHS	None
Edward	Male	56	55	White British	Autism Spectrum Disorder	NHS	ADHD
Jess	Female	25	21	White British	Autism Spectrum Disorder/Aspergers Syndrome	Private	None
Rachel	female	44	43	White British	Autism	Private	ADHD
Brandon	Male	53	49	White British	Autistic Spectrum Condition	NHS	None
Liza	Female	41	37	White British	Autism Spectrum Disorder	NHS	None

Procedures

Ethical approval was received from the University Psychology Ethics Committee (ID: 051331). Participants signed an informed consent form (Appendix D) prior to participation. Interviews took place at the participants' preferred setting (two at the university and eight online via Googlemeet) and lasted approximately 1 hour. Recording was made using a dictaphone or the Googlemeet recording function. The open-ended questions and their order act as a guide to the interviewer rather than being strictly followed. Prompts and follow-up questions were also be asked to clarify meaning and probe for further information. At the end of the interview, participants were debriefed and provided with the debriefing statement (Appendix E). Participants were compensated with a £10 shopping voucher. The interviewer kept a reflexivity log to keep notes of observations and reflections of interview process (Appendix F).

Analysis

A university approved transcriber and S-AY transcribed the interviews verbatim. Non-verbal utterances were noted in brackets. The transcripts were checked against the recordings to ensure accuracy. Identifiable information was redacted prior to analysis.

Data analysis was completed using NVivo 14. IPA was used to analyse participants' responses (Smith et al., 2021). The lead researcher began by reading and re-reading a transcript to gain an initial impression of the data. Initial notes were made to systemically capture observations, which included descriptive, linguistic, and conceptual comments (Appendix G). To adapt the IPA methodology for Nvivo, initial notes that were traditionally placed in the "left-hand margin" were added to the transcripts using the "annotation" function.

Then, the lead researcher identified Personal Experiential Statements that reflected the understandings gained from the initial notes. Personal experiential statements that are

traditionally placed in the “right-hand margin” were coded using the NVivo “node” function. The lead researcher then searched for connections across the Personal Experiential Statements and created Personal Experiential Themes (PETS) through clustering of similar Personal Experiential Statements (Appendix H and I).

Next, the researcher moved on and repeat the same process for the next case until the process was completed for every participant. Finally, Personal Experiential Themes from all participants were exported into Microsoft Powerpoint. Here, the researcher searched for patterns across different cases to create Group Experiential Themes (Appendix J). The analysis process was audited by the research supervisors to ensure the IPA process were completed thoroughly (Appendix K). The principles recommended by Yardley (2017) for qualitative research were applied to ensure quality and rigor of the study (Table 3).

Table 3. Quality Control

Recommendation	Application to this study
Sensitivity to Context	**Methodology considerations and adaptations sensitive to the needs of autistic people** • One-to-one interview has been chosen for its ease of managing interaction and reduce uncertainty for autistic people. • Participants were asked to self-identify if they meet the eligibility criteria and brief questions were asked during the interview to gather information pertaining to autism diagnosis. This method of confirming diagnosis was selected over standardised tests to avoid putting undue demand on participant and over testing that could lead to invalid results (Gowen et al., 2019). • Consultations with autistic adults were sought to ensure study materials were clear and sensitive. • Ensuring participant's individual needs and preferences were honoured as much as possible. For example, using non-stigmatising language and autistic participants' preferred terminology in relation to autism during the interview process (Kenny et al. 2019), asking participants about any reasonable adjustments required and preferred interview location.
Commitment and Rigour	**Supervision** • The lead researcher presented transcripts, annotated notes, and themes to the research supervisors, as well as discussing entries from the reflexivity log. This process allowed the lead researcher's interpretation of the data to be questioned and to have their assumption challenged; it also enabled alternative perspective of interpretating the data to be considered. Themes was also refined as part of this process. The analysis process was audited by the supervisors to ensure steps of IPA were completed thoroughly. **Reflexivity** • The use of qualitative methods like IPA acknowledges the existence of the influence of the researcher on the research process. However, instead of eliminating this influence, qualitative researchers are encouraged to attend to it – a process termed reflexivity (Engward & Goldspink, 2020). As such, the lead researcher of this study kept a reflexivity log throughout the study. The log included notes on the researcher's own thoughts and feelings, preconceptions, and reactions to the research process. Reflecting on journal entries during the analysis process may help to challenge the researcher's own assumptions and reflect on her own influences on the interpretation of the data.
Transparency and Coherence	**Reporting** • Themes resulting from the analysis had been illustrated by extracts from participants in this report. • Sample extracts, conceptual maps, tables/figures of themes are presented in the appendices to illustrate each step of the analysis process and to provide an audit trail.
Impact and Importance	• Limitations of national guidelines on post-diagnostic support and the importance of disclosure discussion post-diagnosis for autistic people was outlined in the introduction. • Clinical implications and recommendations are presented in the discussion section.

Results

The analysis identified six Group Experiential Themes and eleven subthemes (Table 4).

Table 4. Group Experiential themes and Group level Subthemes.

Group Experiential themes	Group level Subthemes
Functions of Disclosure	Accessing Support
	Becoming Myself
	Activism and its Burden
Approaching the Conversation	Managing Disclosure and Responses
	Disclosure Started Pre-Diagnosis
Negative Effects of Preconceptions	Disbelief
	Imposter Syndrome
	Not Having My Needs Met
	Caution and Avoidance
Impact on Others	-
Positive Aspects of Disclosure	Acceptance and Understanding
	Finding Community
Need for Support for Considering how to Disclose and Handling Reactions	-

Functions of Disclosure

This theme describes the reasons why participants choose to disclosure their autism diagnosis to others.

Accessing Support

Participants disclosed their diagnosis for practical reasons in various settings, including employment, and health and social care, to access adjustments and legal protection. Past experiences of being marginalised meant that autistic people felt a need to defend themselves through disclosure. Awareness of situations where they are likely to

be misunderstood also meant that they disclosed in daily life to manage social interactions and stressful situations in the hopes that others would be more understanding towards them.

> *"um, I thought it was useful to have that, to disclose, to have that level of protection. So that if anything I guess if anything went wrong, or I was, I got into a a difficult position of there was some misunderstanding and I felt, you know, what was which was, which put me in a vulnerable position or I felt very uncomfortable about that I would have some extra protection there to to to use" (Eric)*

Becoming myself

Sharing one's diagnosis with others also served a psychological function, allowing participants to be more authentically themselves after years of masking. This was important across both personal and working life:

> *"with friends and close family, it's important to disclose because I think you need to be able to be yourself with those people" (Rachel)*

For others, disclosing represented an act of self-acceptance of their differences. For example, disclosing at his workplace meant that Michael felt less of a pressure to conform to neurotypical social norms and allowed him to be less critical of himself.

"*but I think that feeling of missing out is shorter than the negative feeling I'd have if I went along and was exhausted and really struggling with it…and thinking 'oh but I could have joined in, I could have done this, I could have done that, why didn't I do that when I was there', well if I'm not there in the first place then I don't need to be thinking about it, I'm just, you know, just accept". (Michael)****Activism and its Burden***

For many participants, disclosure also had an altruistic function. Participants talked about the desire to use their disclosure to "*advocate as an autistic person*" and for "*helping*

the autistic community" (Rachel), to "*raise awareness*" (*Edward*) and *"pushing back" (Eric)* against unhelpful narratives about autism, or to hold organisations accountable for inclusive practices and supporting other autistic people:

> *"I've felt empowered now to push them to say a) we should be looking, not necessarily to fill a quota but we should be looking in places where neurodivergent people are because they fill, they fill a lot of the skill sets that we don't have because it's a different way of thinking and b), what allowances can we make as an organisation for people that probably have a lot more struggles than I do" (Josh)*

Participants talked about enjoying and feeling empowered to do this type of work, However, the sense of moral responsibility can also feel burdensome for them. This can be particularly challenging for someone newly diagnosed if they don't yet feel ready to disclose publicly but felt that it is *"incumbent" (Rachel)* for them to disclose if they want to be involved in activism work. Often participants had to consider self-protection and maintaining boundaries, for example, Brandon talked about the challenges and discomfort he faced having "*different compartments coming together*" between his professional and private life when using his lived experience occupationally. Furthermore, the pressure on autistic people to take responsibility in educating others could feel repetitive and exhausting:

> *"I think, that there's this effort involved in it and if you are having to think, right, where do I start with this person? Like what's their level of knowledge and like It's kind of like having to give them Autism 101. And if you're doing that over and over again, it can be tiring." (Liza)*

Approaching the Conversation

This theme described the process of participants approaching the conversation of telling others about their autism.

Managing disclosure and responses

Some participants felt anxious as they were unsure how people were going to react to their disclosure. Jane described ruminating over whether she was "gonna say the right thing, do it in the right way, if it's going to be appropriate". These worries appeared to have impact on how participants disclose. Liza chose to "drip feed" information about her diagnosis to others and had to carefully work out which person she felt "comfortable telling" and who were "safe".

Participants varied on how comfortable they were regarding being open about their autism diagnosis. Some chose to share their diagnosis publicly, such as over social media platforms or to colleagues at work. However, even when they become more open about their autism through time, some still ruminate about potential negative consequences, such as thinking *"am I gonna regret this?"* or *"is this gonna affect me negatively?" (Liza).*

Participants found that managing the conversation of disclosure is a balancing act between openness and preserving others' feelings. Managing disclosure could be tricky as people's reactions varied depending on existing relationship dynamics and people's life circumstances. For Eric, he felt hesitant about disclosing as he was aware of the potential impact disclosure could have on his relationships.

> *"yes, slightly maybe slightly awkward and and I didn't want to cause any argument, I didn't want it to cause a, I didn't want anything to escalate into a falling out. So yeah, it was definitely kind of a tentative or wanting to be open and honest and talk about it but not wanting to almost talk about." (Eric)*

For Helen, being autistic further complicated the situation as she found it difficult to predict how others may react:

"I think its really interesting but that's part of the reason I'm diagnosed, not everyone's interested I suppose (LAUGH). It's hard to tell. … (LAUGH) That's half the problem (LAUGH)."

Disclosure started pre-diagnosis

Many participants began the process of disclosure before receiving their formal diagnosis. Some seek out a diagnosis after discussing the possibility of autism with their loved ones:

> *"I watched that documentary with my wife. And my wife's a counsellor and specialist mentor and has been working with um artistic students in particular, for a number of years… watching that and then doing the AQ test online straight afterwards [giggle] um, and getting quite a high score. um you know, I was immediate - well yeah, you know, that that's it, whereas my wife was was like, no way, no way you can be autistic, surely not, and and then um the more we talked about it and wow, 'maybe maybe'" (Brandon)*

Involving trusted loved ones in conversations about a potential diagnosis and the diagnostic process had allowed some autistic people to feel supported and meant that disclosure of the formal diagnosis felt less of a shock.

> *"And she was really supportive about it, but I think that's because she also had known I was going for this and we have been speaking about it, leading up to it. And so, I think she helped. Already adjusted to it, and accepted it so that maybe that explained why she was so supportive. Erm" (Olivia)*

Negative Effects of Preconceptions

This theme reflects that autistic people's negative experiences of disclosure usually stemmed from people's misplaced preconceptions about autism.

Disbelief

Not being believed was a common experience and participants felt that this is likely fuelled by the perceived mismatch between other people's expectation of what an autistic person is like and the how the participants present.

> *"Erm, yeah (SIGH), I mean there's been scenarios where by there's almost insulting comments where I'd say, someone would say "why do it like this", and saying "well perhaps because I'm autistic and I work in a certain way", and the response is often "you don't look autistic", and its well what does looking autistic look like, or, you know, "you seem really well put together", or people just disbelieving that I'm autistic because I'm fairly high functioning in my career and that sort of stuff." (Josh)*

Participants found that people often associated autism to deficits, whereas their strengths were not recognised.

> *"I think was being very well meaning, but she did say something like, "Oh, I never would have known, you're such an organized person" and she said "It doesn't affect your job", and the implication for me from that, was that she saw autism as something that basically was a negative thing and it should be impacting my job, rather than thinking actually, it might be helping me to do the job I'm doing" (Olivia)*

Participants attributed these assumptions to be influenced by popular media portrayals, myths, and stereotypes of autistic people, such as *"Rainman" (Josh*), "little boys who liked trains" (Jess), or autism is associated with being *"low functioning" (Jane)*. People may also be overgeneralising based on their encounters with autistic people:

> *"Erm so I know for her, she has a brother who is autistic, but in a way that I suppose is much more erm, In line with the common understanding of what autism is. So he was diagnosed young and had a lot of visible meltdowns and things like that, which is very different from my experience. So, I do think that those like stereotypes and ideas do apply to some people. They obviously exist for a reason but they're not things that I identify with…"(Olivia)*

Participants also thought that a lack of knowledge and education around autism often contributed to people being sceptical about their diagnosis. Some participants noticed that there is a generational divide in the level of knowledge and education understanding of autism, which meant that people in older age groups did not know *"what it is"* or *"what to say" (Helen)* in response to a disclosure. Josh's disclosure had even been interpreted by others as him making *"excuses"* and that *"everybody wants a label these days*". He felt that people's lack of compassion towards him is influenced by the increasing incidence of self-identification and people's perception that there is an element of social contagion to autism. Jane also had similar experiences with relatives who thoughts that she had received a diagnosis by reading up about autism and knowing what to say in front of assessors. In addition, she thought that her years of masking may have exacerbated scepticism from others.

> *"she said, 'if you feel that helps you then I'm happy for you, but I don't think your autistic', so that to me was not helpful because, erm, yeah, you know, the person who is supposed to know me the most, my mother, erm it felt like, erm, you know, it wasn't… it was a the opposite of validating it. It was devalidating … I think what I've learned is, it's not so much about me erm cause could be because being a woman, you mask a lot as well. (Jane)*

For others, autistic traits have been so normalised within their family that their signs of autism overlooked, and further contributed to people finding it hard to believe their diagnosis.

> *"I think a lot of discomfort from my side, my family…. family never saw my intense interests as anything other than me being academic…They didn't really think that at seven years old wanting to watch [tv programme] was anything atypical particularly because I come from quite an academic family so I think when I turn round to them and like "well actually I've an autism diagnosis", they were like "you're joking, this is one of your little jokes isn't it". (Jess)*

Imposter Syndrome

Being questioned and not believed after a disclosure had a negative emotional impact on participants and triggered unhelpful thought processes in which some participants questioned themselves about the legitimacy of their diagnosis. This was particularly difficult at a time when they were newly diagnosed.

> *"…and so at that time my conviction felt really fragile anyway, so other people questioning, it really didn't help. It made me feel quite easily shaken and made me question like have I just haven't gone down the wrong path, have I somehow like subliminally convinced the assessor that I am when I'm not." (Olivia)*

These feelings of self-doubt had been described as *"Imposter Syndrome"* (Liza) and the severity appeared to be affected by the timing of the disclosure and whether participants have come to terms with the idea of being autistic after diagnosis. Past experiences prior to receiving a diagnosis also contributed to this sense of "Imposter Syndrome". Helen talked about her experience of emotional abuse in childhood meant that she tends to question herself even though "autism makes sense" logically. For Liza, the uncertainty around her diagnosis during the assessment process further played a role in her "Imposter Syndrome":

> *"she (psychologist) was like, "you you were very, very clear on like the sensory stuff, and very clear on like the communication stuff", but it was like the the need for routine and things, that I think I was kind of like borderline… so the fact that she had to go and double-check, made me feel like, well it's not clear and I'm not like I'm not autistic enough… So it was good that I got that kind of "yes you are" but it was, it feels like it was like a bit touch and go, and like, and and so I came away from that thinking like, well, would like… and I knew the quite a lot about autism. So I was like, "well, am I just putting it on?" Am I saying what I think I need to say." (Liza)*

Interestingly, the contributing participants to this subtheme tended to be females (except one participant who was non-binary), and could be influenced by the male biased in diagnostic criteria and women usually being underdiagnosed.

Not having my needs met

Participants felt that people's assumptions and lack of understanding about autism meant that, not only did disclosing their diagnosis not lead to the desired effect of having their needs met, but they were also either dismissed or discriminated against. Jess had experienced when she requested reasonable adjustments at university:

> *"they're like "well everybody else manages so why do you need adjustment, if you need adjustment maybe you shouldn't be here", and I had the University say that to me, they were like you know "maybe reconsider your [degree]. It's nothing to do with my academic ability, it's because they did not want to accommodate" (Jess)*

Other participants had also had experiences of not getting their needs met across a range of contexts including employment, healthcare, and statutory services which were frustrating for them. Participants found that organisations were often either had rigid rules around who to give support to or what type of support to give, and these were not set up to accommodate individualistic needs of autistic people across the spectrum. Tina found that social services did not seem to understand "*neurodiversity can also be debilitating"* and were not able to offer her appropriate support due to autism not being a *"physical disability"* (Tina).

Even when adjustments were offered, participants felt that these were not always timely and did not fully meet their needs. At times, participants felt that efforts to making reasonable adjustments were not managed appropriately due to the lack of knowledge and confidence, as Brandon had experienced:

> *"Um my manager was very sympathetic. Um and I would also say, didn't get it at all [laugh]… I think really. was really probably worried about doing the wrong thing and*

therefore just said, yes to everything and and but, but actually, you know, I, some things have improved, but most things are not really…' That was almost worse because it's like, well, hold on your yours, you know. You're just saying, yes, just like that without considering what the consequences are for the organisation…So it I got what I was asking for [laugh], which is great, but I also felt at the same time like it was a bit of a knee-jerk response rather than a careful weighing and yes, that seemed sensible." (Brandon)

In addition to not getting practical needs met, participants also described unmet emotional needs. With participants having relatively low support needs and being able to get by, some participants felt that loved ones did not recognise the significance of the diagnosis for them and well-meaning responses were experienced as invalidating:

"He kind of went "well, you know it doesn't really make a difference to who you are. It's just a label." Like I don't think he really understood why I wanted to go and have the diagnosis. … And I don't know whether I kind of maybe took that as slightly unsupportive because he didn't understand that it meant quite a lot to me but I don't, I don't think that he meant it to be like that. I think he meant it quite supportively that, you know, 'it doesn't matter because you're still the same person to me.'" (Liza)

Furthermore, the constant need to remind others about their autism and adjustment needs could be exhausting as it served a constant reminder of their limitations:

"I think cos it's, because it's relatively hidden… but I think people quickly forget that that's the case and so its felt sometimes that I just needed to keep reminding people that, you know, this is a situation, this is the condition that I have, these are the difficulties that I have, this is how you can help me, erm so I would have hoped perhaps they would have been a bit more of remembering and understanding rather than perhaps the responsibility back on me to keep telling people about, about it and how it affects me…it reminds me of the things that I, that I struggle with, that

I'm aware that I'm, it's just really difficult for me to do, erm and I think that's what stirs up the negative feelings sometimes around it." (Michael)

Caution and avoidance

Negative experiences of disclosure could have an impact on participants' their future engagement with services and subsequent disclosure behaviours. For example, Edward felt "*reluctant to go back to the clinic again"* after getting "dysregulated" by healthcare professionals not understanding his needs. Other participants talked about the need to weigh up the risks and benefits of disclosure, and choosing nondisclosure when the perceived risks outweighed the benefits. For example, Michael chose not to disclose in situations where he does not expect any changes to happen, after experiencing his employer not knowing how to support him and being unsure himself what adjustments was available:

"Mm, you see I suppose it's thinking 'well what am I going to get, what's going to be achieved by me disclosing, talking to people, what's the result going to be', and if I can't see that there's a difference, a change as a result of it then I suppose that's the reason why I wouldn't necessarily tell people." (Michael).

For some participants, nondisclosure became the default and many became more cautious about who they disclose to, especially when they anticipate negative reactions, discrimination, or if they expect people's attitude to change towards them due to the aforementioned *"preconceived ideas" (Olivia)*:

"I think I'm to a degree guarded upon who I decide to disclose to…Erm, especially in a, in a professional setting, erm I don't, whilst I know it shouldn't, I don't want disclosure to hinder my progress or how people treat me at work, erm so yeah, I think there is an element of guardedness involved. (Josh)

Some chose to use partial disclosure strategies as a form of self-protection, only sharing what is required to get their needs met, rather than sharing full details of their autism diagnosis:

> *"So yeah, started getting this service, so I won't again I won't say to them.' Oh yeah, I'm autistic'. I will say, all right, you know, I struggle sleeping, so can we make it afternoon when you come to pick it up and drop it off. That sort of thing. So you sort of erm, there are times when you don't need to say, you can just um especially when you think it might change people's attitude or behaviour towards you." (Tina)*

Brandon also talked about having to pick and choose which aspects of their autism he shared with potential employers as he could not trust that he wouldn't be written off straight away if he asked for adjustment".

> *". But I, I waited for the right moment in terms of where it was a relevant to an answer I was giving so, you know, so I didn't talk about it in terms of asking for any assistance or any adjustments, but I talked about it in relation to why I would be good…" (Brandon)*

Impact on Others

This theme describes the impact disclosure has on people on the receiving end of disclosure. Participant's disclosure often led others to consider what their loved one's diagnosis or autism means for them. Some participants had reflections from others about their own neurodiversity:

> *"…and they're great about it and I often get emails saying 'I've often thought about myself" (Helen)*

whereas for others this may be too difficult to think about in the moment:

“My dad like really reacted badly to it but my dad is actually the person in my family who has the most traits and characteristics erm so I always wonder whether that he saw a lot of himself in me and is now slightly perturbed potentially (LAUGH) by the fact that maybe he fits the criteria. He will never admit that… (Jess)

For some parents receiving the news of disclosure, it was sometimes difficult to accept and triggered feelings of guilt:

“she felt very like stuck that it was a bad thing like a really negative thing and also maybe erm, was a sign that she haven't parented me well, or something like it was something that was her fault and was also really I guess might mean that, I was just going to have a really unhappy life.” (Olivia)

Participants also found that time and further was required for loved ones to process and adjust to the diagnosis:

“you know, cos my family for the most part have just gotten over it, its taken them a long time don’t get me wrong, like its taken them years to be able to have a discussion with me about the nature of autism and about autistic culture and rights and stuff. But these days, like my mum is one of my biggest advocates…”. (Jess)

and that there was a level of uncertainty that participants had to learn to tolerate:

I think, I think that's what I've learned from my experiences so far, is that you can't control, I mean, it's an autistic thing to want to control an environment, to want to control a response, to control the conversation, because you feel safer. And I think what I've learned is that you just got to trust people, you know, if they're a good friend, and they care then that's all that matters really, and they'll go away and they'll deal with it in whatever way they think best.” (Rachel)

Positive aspects of disclosure

This theme represents what contributed to positive experiences of disclosure.

Acceptance and Understanding

Participants often associated positive experiences with people who responded in a way that was open, curious, willing to listen or drop any preconceptions they have.

> *".I remember her just being very much wanting to know how I was feeling rather than her jumping in and being like, 'Oh that's great' or 'Oh it's terrible'. I think that was again maybe why it was such a positive experience because I felt like she was waiting to hear how I felt, and then was going to kind of take my lead on that erm rather than jumping to her own conclusions. erm, so whether she had negative views about it or not, I never really knew because she just went with what I said if that makes sense. (Olivia)*

In general, having pre-existing knowledge, progressive views, or lived experiences of neurodiversity or disabilities, were also associated with positive attitude towards disclosure:

> *"Yeah, I think it's it's made me feel more optimistic that for people who already know a bit about disability, or might be disabled themselves, I'm probably not going to get this really intense, shocked reaction, erm yeah, I guess maybe now that I've had so many of those reactions, I kind of it's almost like I take it for granted a bit, and I kind of just expect that now [laugh] for most people who especially just working in the field, but I mean, and, friends I have and their backgrounds, like I would probably be quite shocked if someone didn't react in that sort of way who's in like current circle. But yeah, at the time it was like a real relief and now I've kind of came to see it as like that's the norm…" (Olivia)*

Others' acceptance and openness did not only make participant feel relieved, but also meant they could work together to consider ways of meeting the autistic person's needs.

"So, yeah, my brother is really read up about it a lot and investigated, how we can support me and he's discussed with me things like, say, he's taking me to an event or a medical appointment or something, erm how best he can support me. So things like finding the quiet quiet place to be possible and probably sitting down. and, and perhaps, erm I carry a [item associated with special interest] around with me now… that calmed me down greatly…And and it's really greatly appreciated." (Tina)

Finding community

Many participants found that disclosure opened opportunities for them to connect with others, including other autistic people, those considering their own neurodiversity, or allies, and felt celebrated.

"I got another friend who's brother and sister are autistic and he also looks and supports somebody else who's autistic, and they're both around. And I said, "Look, I'm autistic" and the one that was autistic was like, "well, you know, you've just joined the most interesting club in the world. You're gonna meet some amazing people…. So erm that that was really heartwarming erm to hear that." (Jane)

Some found opportunities to take part in community groups where they were able talk openly about autism and share experiences.

"he was running some, some dialogue sessions and I got involved in that, gotten load out, it was just great. Really liked it, you know. Um really helpful at that point, and meeting up with other autistic people and neurotypical people being able to talk about all sorts of things." (Brandon)

These experiences had a normalising effect on the autistic experience and brought participants sense of belongingness and hope.

"… knowing other people in real life that are all like, doing okay, they've got jobs that they are really happy with. that they've got partners that they are really happy

with, and, I know them personally and they just seem like, nice decent, people like that stuff It's really reassuring, and that's the stuff that feels like kind of, destroys the stereotype the most for me." (Olivia)

Need for Support for Considering how to Disclose and Handling Reactions

The support received for disclosure varied across participants. Some received minimal support beyond a letter confirming diagnosis. Participants often had to seek out information themselves and even though this was considered within their own capabilities, support often felt lacking.

"it felt very much the time that you get your diagnosis and then you, you walk out of the that that centre in… you, you know, you feel like your world's changed. I'm autistic now, so and then but then there's nothing to help. They give you a list of resources and and internet links and books and stuff but it's very much you're on your own." (Jane)

A minority of participants were able to access advocacy services to support disclosure or private therapy to talk about disclosure. Some accessed post-diagnostic support from their diagnostic service or through community groups. Participants often found support from others helpful, whether these were one-to-one or in groups, from professionals or autistic people., Participants saw value in being to hear the experiences of others disclosing and having space to think about disclosure:

"I suppose there'd be different elements with the disclosure, there's the fact of actually deciding to tell people and deciding who to tell but its maybe handling people's reactions and not necessarily talking for me but more in general terms, what if you know, somebody discloses and the reaction they get from family members or colleagues at work, if they're in work, is almost negative and it's not what they were expecting, how does somebody deal with that and if there isn't that

support there, you know, somebody that you can go to and say "I need a bit of help here." (Michael)

Discussion

This study aimed to explore autistic adult's experiences of diagnostic disclosure and non-disclosure. Critical Approach and Intersectional theory of disclosure and closeting (McDonald et al., 2020) stipulated that revealing a difference can have both negative and positive impacts. We found that autistic people's decision to disclose could be influenced by these expectations of positive impacts across practical, personal, and systemic levels. In line with previous research within employment and broader context (Lindsay et al., 2021; Huang et al., 2022), this study found that autistic people disclose for the purpose of accessing adjustments, and to strive for support and understanding from others. However, for autistic adults who sought a diagnosis in adulthood who typically have relatively low support needs, disclosing a diagnosis also serves as an emotionally restorative function of self-acceptance. Being their authentic self means resisting the need to mask (Bradley et al., 2021) and in the long term this could be more beneficial for autistic people's mental health and reduce burnout (Raymaker et al., 2020).

Activism is an additional function of disclosure that this study has identified. Analysis of autobiographies of autistic people have drawn parallels between autism disclosure to disclosure in other minoritized groups, which act as a form of resistance against oppression (Davidson & Henderson, 2010) and challenges the power imbalance in institutions maintained by collective closeting (McDonald et al., 2020). However, we also found that the moral obligation to undertake such work can also be exhausting for autistic people due to the need to repeatedly disclose. Furthermore, it could feel like autistic people are taking disproportionate amount of the burden for this work, much like people from ethnic minoritised groups, who are often expected to take on responsibility for equality, diversity, and inclusion work (Van Laer & Janssen, 2011).

Promisingly, positive experiences of acceptance and understanding from others featured in participant's accounts in this study, and for some, these were the norm rather than the exception. This is perhaps unsurprising given the increasing public awareness of autism (Dillenburger et al., 2013) and increasing number of people diagnosed in adulthood (Lai & Baron-Cohen, 2015), but this was encouraging to see. This study also found that disclosure brings opportunity to build connections. Community connectedness and collective self-esteem (perceived positivity of autism identity) had previously been suggested to be linked to increased self-esteem and improved mental health in autistic people (Botha et al., 2022; Cooper et al., 2017).

An objective of this study is also to understand the context around non-disclosure. Intersectional theory (McDonald et al., 2020) suggests a link between closeting of "invisible, non-normative, and stigmatised" differences and oppression. Having an autism diagnosis could be considered to fit this definition of a difference, and indeed, this study found that many autistic people chose not to disclose because they want to avoid negative reactions and discrimination, which they were able to predict based on experience. Autistic people viewed negative experiences to be influenced by people's preconceptions about autism. These preconceptions may have been formed due to exposure to the media portrayal of autism and from their personal experiences interacting with other autistic people. In line with previous research (Huang et al., 2022), mismatch between people's expectations of what autistic people look like or are capacity of and how they present meant that disclosures were often met with scepticism. These experiences could be particularly disrupting for newly diagnosed autistic people who going through their own process of adjustment.

Not being believed by others could have a psychological impact on the autistic person disclosing, leading them feel uncertain and doubt the legitimacy of their diagnosis. The term "Imposter Syndrome" had been used to describe these psychological

experiences in a recent study by Harmens et al. (2021) in blog posts written by self-identifying and clinically diagnosed autistic women. Having to explain to others why they do not fit stereotypes can exhausting for autistic people. While not being believed by others is not a female only experience, “Imposter Syndrome” may be more common in females and those with late diagnosis given male bias in autism diagnosis and the use of camouflaging strategies (Cruz et al., 2024; Bradley et al., 2021). Not feeling believed and feeling like an “Imposter” may contribute to poorer mental health, given that external source of autism acceptance had been shown to negatively predicted mental health outcomes, including depression and stress (Cage et al., 2018).

Not having a disclosure taken seriously could become a barrier to autistic people getting their needs met and could deter autistic people from making further disclosures or from engaging with services to avoid negative reactions, inaction, discrimination, and prejudice, concurring with previous findings on nondisclosure (Dugdale et al., 2021; Huang et al., 2022). Our findings contribute to existing intersectional theory that discrimination could occur when multiple forms of differences and identity intersect each other. In the case of autism disclosure, being female and appearing “able” seemed to exacerbate negative responses to disclosure.

For loved ones on the receiving end of disclosure, unexpectedness of the news could be challenging emotionally, and may trigger a range of feelings associated with Kubler-Ross’s five stage theory of adjusting to grief and loss (1969). Feelings such as shock, denial, and guilt had also been documented in the parents’ accounts of receiving the news of their children’s autism diagnosis (Fernandez-Alcantara et al., 2016). However, resolution through progress acceptance, positive changes in family dynamics, and effort, were also evident in parents’ account. Likewise, loved ones’ ability to adapt to a late diagnosis disclosure through time and ongoing conversations were also featured in autistic adults’ accounts in this study. In addition, involving trusted loved ones in discussions about

a possible diagnosis meant that loved ones were able to support autistic people through the diagnostic process and beyond.

Post-diagnostic support for disclosure varied widely across participants. This disparity is not surprising considering the lack of detailed guidance for post-diagnostic support (NICE, 2012). Being able to hear about others' experiences of disclosure and talk through their decisions and reactions in relation to disclosure were deemed helpful for autistic people. Recent qualitative research using autistic-led post-diagnostic psychoeducation programme (Crane et al., 2023) had also found preliminary support for these type of group interventions.

Strengths and Limitations

This study benefitted from consultation with autistic adults, reflexivity, audit, and adherence to good practice recommendations for qualitative research. However, while an effort was made to select a homogenous sample, there were some factors that could have contributed to heterogeneity, including gender, wide age range of included participants (between 25 to 61 years), time elapsed since receiving the diagnosis (between 0 to 8 years), whether a diagnosis was received from the NHS or privately, and co-occurring neurodevelopmental conditions. Only information about gender identity was collected but not biological sex. The ethic group of the sample was predominantly white British, and findings may not be generalisable to the global majority. It is unclear how the intersection of these characteristics influenced disclosure. While details about participant's clinical diagnosis were collected, no standardised assessments were used, which was a trade-off between reliability and not over-testing research participants.

An additional factor that contributed to heterogeneity was the larger number of participants than usual included for interview and analysis compared to relatively smaller sample required for IPA research. Twelve participants were interviewed to account for

potential data loss and poor interview quality, however, as these did not occur it mean that unexpected high number of interviews were included in the final dataset. The large dataset and heterogeneity made analysis particularly challenging and development of group experiential themes feels too “superficial”.

Clinical Implications

On a service level, discussions around disclosure should be incorporated into routine follow-up appointments for newly diagnosed autistic adults. Services should consider providing different format of post-diagnostic support, for example, either in groups or one-to-one to suit individual needs. Given the benefits of connecting with other autistic people and sharing of lived experiences disclosure could bring for newly diagnosed autistic people, services should consider developing roles for autistic people to led and deliver post-diagnostic intervention, in the form of one-to-one peer support and support group. At the same time, it would be important for service managers and supervisors to consider the impact of partaking in the delivery of these interventions for autistic employees, and to discuss these within line management and supervision, to ensure that autistic people’s privacy and work life balance is protected.

On an individual level, ongoing support sessions over a period of time immediately or shortly after a diagnosis could be helpful for autistic people to start considering disclosure. It may be helpful for clinicians and autistic people to discuss who they feel safe to disclose to, the depth of information required to be shared in different context, and different method of disclosing. It would also be important for clinicians to consider how interactions of other differences and identity that an autistic person possesses, as well as the extent of stigma within autistic person’s systems, could impact on the disclosure experiences. It is important to be aware that disclosure could trigger different reactions and emotional experiences for the autistic person and those around them, therefore clinicians may wish to consider with autistic people how to manage these situations.

Conclusion

Whether autistic adults disclose their diagnosis is a context dependent decision. Disclosure could bring a sense of connection and being understood for autistic people and for some may represent an important act of self-acceptance and activism, though this can present a personal burden. Diagnostic disclosure may open opportunities for autistic people to access much needed support. However, people's preconceptions of autism could lead to negative consequences, such as discrimination, that create barriers for autistic people to get their needs met and discourages further disclosures. Given the potential risks and benefit of disclosure, it is important that clinicians to incorporate discussions about disclosure, including insights from experiences of others and consideration of potential consequences as part of post-diagnostic support for autistic people.

Contributions

SA-Y conceptualised the study. SA-Y wrote the study protocol and MF gave feedback on the study protocol which was amended accordingly. SA-Y collected the data and completed the analysis and write-up. AT and MF supervised and audited the analysis process. MF gave feedback on the final write up of the study.

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Appendix A

Interview Schedule

Demographics Questions

1. What is your age?
2. What gender do you identify as?
3. What is your ethnicity?
4. What was the official diagnosis you received? (Prompt: was it ASD, Aspergers' Syndrome, high functioning autism, PPD or other (please state)?
5. What is your preferred terminology?
6. What was your age when you received your diagnosis of [INSERT PREFERRED TERM]?
7. What is the name of service that gave you the diagnosis of [INSERT PREFERRED TERM]?

For this study, *diagnostic disclosure* means when a person tells other people about their autism diagnosis. For this interview I am interested in you and your experiences. There are no right and wrong answers to any of the questions. I will ask you around 10 open questions and will let you talk freely. I will say very little during the interview but might ask you some follow up questions in between to clarify what you are saying or ask you to expand your answers.

Questions on Disclosure

- Can you tell me about the first time you told someone about [INSERT PARTICIPANT'S PREFERRED TERMINOLOGY]?
- How is this experience similar or different to later experiences of disclosure you've had?
- To what extent has the experiences of disclosure been what you expected it to be like?
- How have these experiences affected you?
- Have you done/would you do anything differently because of these experiences?
- How important is it to tell others about your diagnosis Were there times when you decided not to disclose your diagnosis?
- Have you received any support around telling others about your diagnosis? (If yes – what has been helpful and is there anything you would liked changed; if no – would you have liked support and what would be helpful?
- Is there anything else that you would like to tell me about your experiences of disclosure that I haven't asked about?

Prompts:

- Tell me more…
- What did you make of it?
- How were you with it?/What do you think about it?/How did you feel about it?
- What does that mean to you?
- What was it like?
- Why?

Appendix B

Participant Information Sheet

What is the purpose of the study?

The purpose of this research project is to find out about autistic adults' experience of *diagnostic disclosure*. Diagnostic disclosure means telling other people/organisations about your autism diagnosis. We are interested in this because we know that there are increasing numbers of adults receiving an autism diagnosis and we want to understand how we can better support autistic people after getting a diagnosis.

What are the criteria for taking part?

We are looking for people who are:

- Adults age 18 or over
- has a formal diagnosis of Autism (e.g. Aspergers Syndrome, Autistic Disorder, high-functioning autism, Autism Spectrum Disorder, Autism Spectrum Conditions, Pervasive Developmental Disorder etc.)
- Received their diagnosis in the United Kingdom (UK) within the last 10 years
- Living in the UK

What will I have to do?

If you agree to take part, you will be invited to take part in a one-to-one interview with a researcher, who will be asking you some questions including:

- **Information about you** (e.g. age, gender, ethnicity, details about your diagnosis, where and when you received your autism diagnosis, your place of residence)
- **Your experience of telling others about your autism diagnosis**
- **Situations when you decided *not* to tell others about your diagnosis**

The interview will be audio recorded and the researcher will ask for your permission before starting the recording. If you wish for the recording to stop at any point, or to take a break, you can let the researcher know at any point during the interview.

Where will the study take place?

For your convenience, you may take part in the interview either:

1) in person at the University of Sheffield, or
2) online via googlemeet

In person interviews will usually take place at University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT.

For online interviews, the researcher will send you an email link to join the meeting online.

What do I do if I want to take part?

If you would like to take part in the study, please contact the lead researcher by email sauyeung1@sheffield.ac.uk (Sheena Au-Yeung, Trainee Clinical Psychologist) to confirm that you would like to take part. You will be asked to sign an informed consent form and the researcher will arrange a date and time to meet you, either online or in person. The researcher will be happy to answer any questions you have about the study before you take part. You may also wish to tell the researcher about any additional needs and reasonable adjustments you require.

Do I have to take part?

No. Participation is entirely voluntary. If you change your mind about taking part in the study, you can withdraw at any point during the interview or at any time during the week following completion of the study. After this time, the interview data will be transcribed from audio to text by the researcher or a university approved transcriber to allow data analysis to begin as soon as possible. You may withdraw from the study by contacting the research team by email (sauyeung1@sheffield.ac.uk or m.freeth@sheffield.ac.uk). You do not need to give a reason for why you choose to withdraw. If you decide to withdraw, all your data will be destroyed and will not be used in the study.

What are the benefits of taking part?

There are no immediate benefits of taking part in the study for research participants. However, we are hoping that the knowledge gained as part of this research project will help us improve support for autistic people after getting a diagnosis.

What are the risks of taking part?

The questions in this interview will ask about your experiences of telling others about your autism diagnosis. We understand that some of these experiences may be upsetting to talk about, so you can stop the interview at any time and leave any questions you do not wish to answer. If you do feel distressed, please talk to someone you trust, or contact the below organizations who are able to offer support.

Samaritans: http://www.samaritans.org/how-we-can-help-you/contact-us or text 116 123 (UK) or email jo@samaritans.org

Mind: http://www.mind.org.uk/information-support/helplines/ or call 0300 123 3393 or text 86463

Will I receive any reimbursement of expenses for taking part in this research?

After the interview, you will receive a £10 e-voucher to compensate for your expenses. Your full name and email address will be stored securely by the Departmental/University finance teams for 7 years, in case of a financial audit.

What will happen to my data?

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). All information collected about you will be kept strictly confidential. 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). The researcher would discuss the need to breach confidentiality with you if it is practical and safe to do so; the aim of this would always be to support yourself and those you mention and ensure safety (for example, it may involve letting relevant services know about the situation to help provide those involved with support). If safeguarding concerns arise, these will be reported to the head of department at psy-hod@sheffield.ac.uk.

All research data will be given a unique number, with no way of identifying you. Your research data will therefore be anonymous. All audio recordings, original interview transcripts, and personal identifiable information will be deleted once the trainee complete their clinical psychology doctorate programme. All identifiable data will be redacted in the transcripts prior to data analysis.

Your interview data will be stored securely in a password-protected file and any hard copies will be stored in a locked cabinet, which only the researchers will have access to. The anonymous data collected from all completed interviews will be analysed and the findings written up in reports, including the trainee's doctoral thesis, lay summaries, academic papers, published in peer-reviewed journals, presented at conferences, and used to develop future research and/or training workshops. If any quotes from your interviews are used in the reports, these will be done anonymously using pseudonyms. Therefore, there will be no way of identifying the individuals involved. The lead researcher's research supervisor will take responsibility for data destruction. Anonymised transcripts will be kept for a period of 10 years and destroyed at the end of the 10-year period.

This project has been ethically approved via the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure (ID XXXXXX).

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.

Questions?

If you have any questions about the study, please contact us by email:
Lead researcher: Sheena Au-Yeung (Trainee Clinical Psychologist)
email: sauyeung1@sheffield.ac.uk
Supervisor: Dr Megan Freeth
email: m.freeth@sheffield.ac.uk

Complaints

In the first instance you can contact the lead researcher, Sheena Au-Yeung on Sauyeung1@sheffield.ac.uk. Alternatively, you can contact the research supervisor involved in the project; Megan Freeth on m.freeth@sheffield.ac.uk

If you feel that your complaint has not been handled to your satisfaction following this, you

can contact Prof Elizabeth Milne (Head of Department) on psy-hod@sheffield.ac.uk, Prof Glen Waller (Head of CAPU) on g.waller@sheffield.ac.uk, or Rebecca Dennis (Director of Ethics) on psy-ethics@sheffield.ac.uk.

Appendix C

Study Advert (online, e.g. twitter/facebook)

Twitter/facebook post template.

As part of my clinical psychology doctoral training, I am conducting a research study exploring autistic adults' experiences telling others about their autism diagnosis in the UK. Please see the poster for more details on how to take part.

Poster wording.

Research study on autistic adults' experience of diagnostic disclosure

Researchers at the University of Sheffield are currently conducting a research study exploring autistic adults' experiences of diagnostic disclosure (telling others about their autism diagnosis). We are looking for:

- Adults age 18 or over
- has a formal diagnosis of Autism (e.g. Aspergers Syndrome, Autistic Disorder, high-functioning autism, Autism Spectrum Disorder, Autism Spectrum Conditions, Pervasive Developmental Disorder etc.)
- Received their diagnosis in the United Kingdom (UK) within the last 10 years
- Living in the UK

The study will involve taking part in an 1 hour interview with a researcher either online or in person at the University of Sheffield. For further information or to express interest in the study, please contact sauyeung1@sheffield.ac.uk or see the Sheffield Autism Research Lab (SHARL) website for more details.

Appendix D

Informed Consent Form

Study Title: A Qualitative Study on Autistic Adults' Experiences of Diagnostic Disclosure
Participant ID:

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Project		
I have read and understood the project information sheet dated **24/01/2023** or the project has been fully explained to me. (If you will 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.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will include being interview and audio recorded.		
I understand that my taking part is voluntary and that I can withdraw from the study at any time before or during the interview, or up to a week after the completion of the 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.		
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.		
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.		
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.		
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.		
I give permission for the research data to be stored for a period of 10 years and I understand that these will be destroyed at the end of the 10 year period.		
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.		

Name of participant [printed] Signature Date

Name of Researcher [printed] Signature Date

Project contact details for further information:
Principal Investigator: Sheena Au-Yeung (Trainee Clinical Psychologist), email: sauyeung1@sheffield.ac.uk
Research Supervisor: Dr Megan Freeth, email: m.freeth@sheffield.ac.uk

Copies:
Save 2 copies of the consent form: 1 paper copy for the participant, 1 copy for the research data file

Appendix E

Debriefing statement

The aim of the study is to explore the autistic people's experiences of diagnostic disclosure (telling others about their autism diagnosis. We hope that the findings of this study will help improve support for autistic people after receiving a diagnosis and we are hoping that our findings help us come up with recommendations for those who work with or provide support to autistic people.

The findings of the study will be summarised in a research report after the completion of the project. If you would like a copy of the report, please let the lead researcher know, and a copy can be sent to you by email.

We understand that talking about experiences around your diagnosis can be difficult and we appreciate you sharing your experience with us. Please find below a list of resources which you may find helpful.

The Sheffield Autistic Society is a local charity supporting autistic people and their families – more details can be found on: https://sheffieldautisticsociety.org.uk/contact-us/

National Autistic Society is a national charity providing support, guidance, and advice for people on the autism spectrum and their families, more details about them could be found on: https://www.autism.org.uk

A-team Social Group - is a group for adults on the autism spectrum with regular online and face to face activities. For more information, see https://sheffield-aspergers.org.uk/a-team-social-group/

Samaritans: http://www.samaritans.org/how-we-can-help-you/contact-us or text 116 123 (UK) or email jo@samaritans.org

Mind: http://www.mind.org.uk/information-support/helplines/ or call 0300 123 3393 or text 86463

Appendix F

Extracts from Reflexivity log

Date:_17.03.2023

Stage of research: interview
What was happening /what were you doing:

Participant 4 seemed distressed at the start. Effort made to ensure participant understood their rights if they wish to withdraw.
Participant also commented on how demographic question on gender was asked as they felt that sex is just an important as gender.

What came into mind (thoughts, feelings, assumptions, reflections)) and when (before, during, after)?

The initial "rupture" and repair actually made the interview feel more natural and it flowed well. Almost felt like a projection of the participant's life story of being misunderstood initially but then gaining understanding and support which allowed her to thrive.

What are my learnings/Anything I would like to do differently?

-Need to list demographic as a limitation.
-Need to be more sensitive when it comes to gender ideology issues.

Date: 03.01.2024

Stage of research: Analysis

What was happening /what were you doing: listening to audio recording of interview with Participant 2

What came into mind (thoughts, feelings, assumptions, reflections)) and when (before, during, after)?

Feeling very moved by the discussion about community and empowerment. Felt very drawn to his story. Felt that interview was deeper than I realised during the interview stage.
Am I relating to him because of the work that I do? Thinking about my position working within community psychology setting and working with those who are "oppressed" by the system. Will my position influence how I read his quotes?

What are my learnings/Anything I would like to do differently?

I've become more aware of my position and propensition to align with people with a social disadvantage. While I don't see this as a "bad thing", I need to be aware of how this would influence how I portray autistic people within my research.

Appendix G
Sample extract of a transcript

P = Participant , R = represent research
Types of comments: **Bold** = descriptive, underline = conceptual, *italic* = language

Personal Experiential Statements	Extract from Josh	Initial Notes
Expectation of polarising responses	R: Okay, and so my next question is to what extent has the experience of this disclosure been what you expected it to be like? P: **Yeah I'd say that's almost exactly as expected, I expected there to be a bit of a split whereby it'd be very, it'd be polarising very positive experiences or very negative experiences and not much in the middle. That's pretty much what I expected if I'm honest.** R: **And how did those experiences make you feel?**	Experiences were polarising. black and white thinking
Expectation of a range of responses led to feeling indifferent	P: **Erm, (SIGH) indifferent to a degree, I wouldn't really say I lose any sleep over it, its as I kind of expected it, the anticipation was there.** R: That's interesting that you feel indifferent, tell me a bit more about that. P: **Erm, I suppose it's the expectation isn't it, so if you expect something to happen and it happens, there's not gonna be any surprise.** R: So I just want to clarify, so is that what you sort of expected?	Expected polarising views, therefore felt indifferent to them. Does that mean not meeting expectation would lead to more negative feelings?

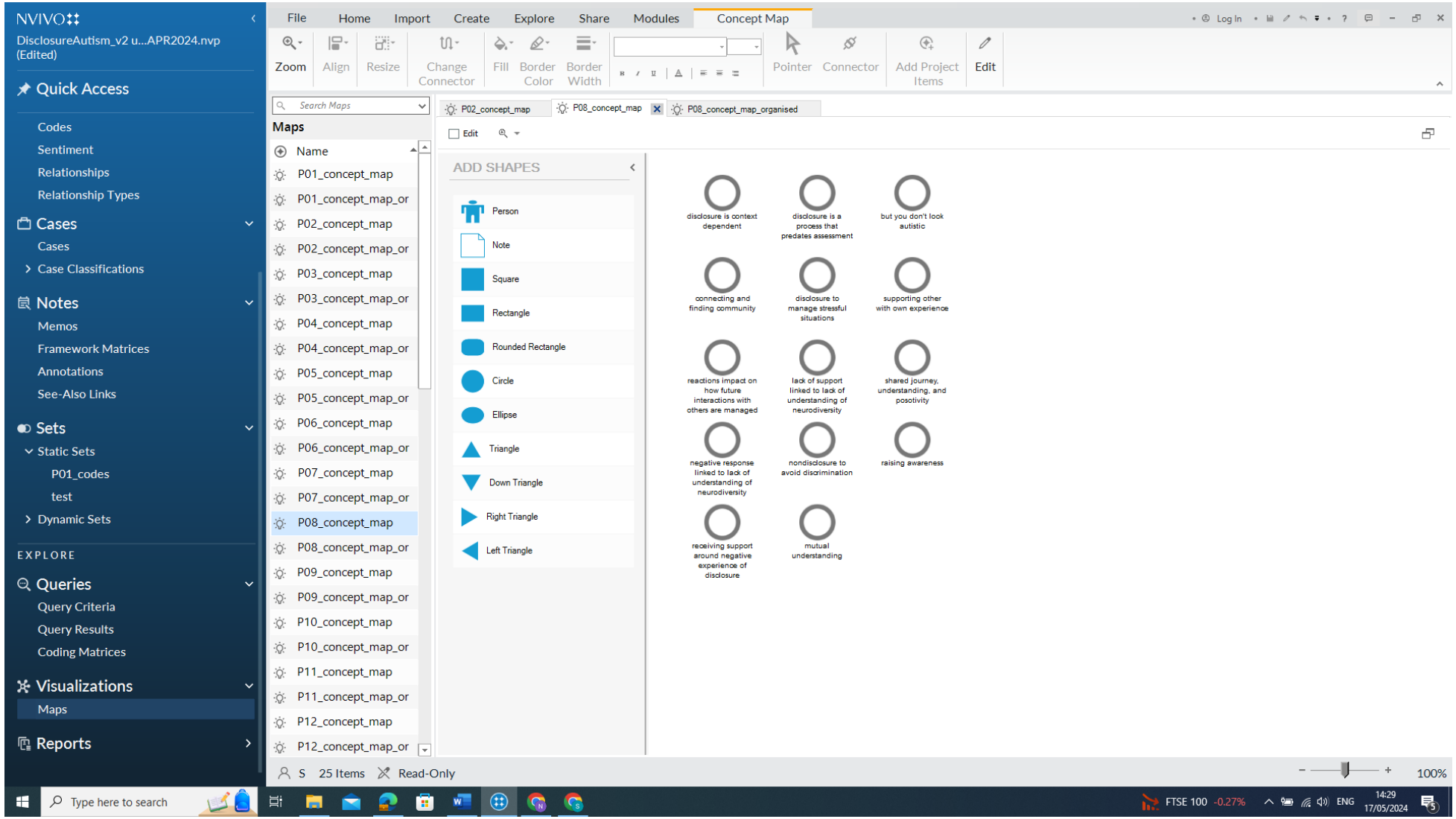
Response to disclosure depends on knowledge of autism	P: **Yeah I expected it to be polarised and I expected to a degree, you know, that it would be very positive reactions or very negative and not much in the middle.** R: Okay, okay, is there anything else you want to add to that? P: No I don't think so. R: **Okay great, so why do you think that there's this polarised term?** P: **Probably lack of education.** **R: Education yeah.** **P: Yeah I think it's a lack of understanding of I suppose mental health disorders in general but also neurodiversity's, erm I don't think people understand them well enough. Yeah I'm autistic myself and I wouldn't proclaim to understand it well enough**, *you know the studies are going on and on and you know, everyone's trying to, trying to understand and especially with it being such a wide spectrum, erm you know its not like, its not like obesity when you look at someone, like me (LAUGH), you know you have someone that's underweight, you have someone that's normal weight, you have someone that's obese, you can physically see that but whereas when you have people*	polarising responses linked to lack of under-standing of neurodiversity. metaphor - comparing to obesity - obesity can be seen whereas autism is an invisible condition.

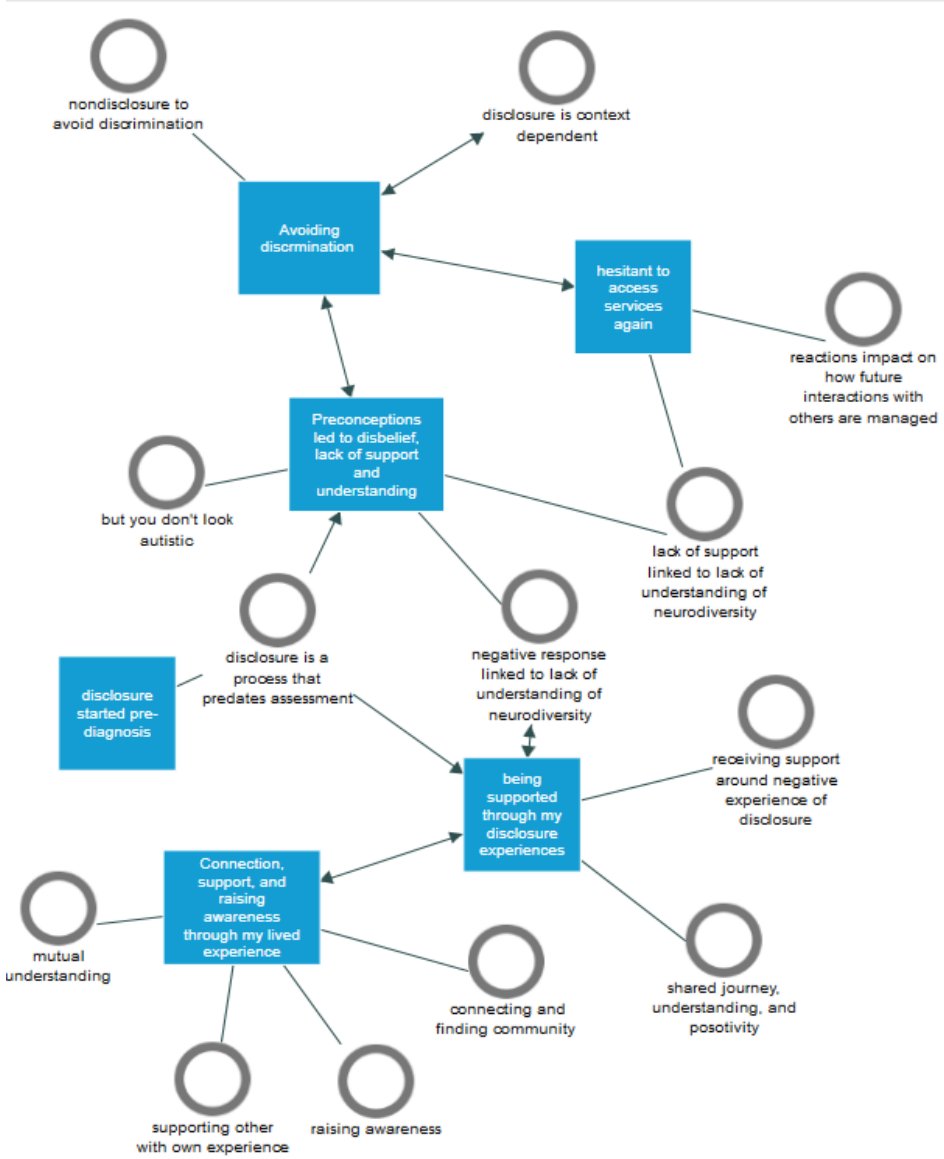
	who are autistic you cant see the difficulties they've got or where they are on that spectrum, I think people almost expect it to be a linier when its more of an explosion from a centre with different points, ***erm so yeah I think its just a difficult concept to understand in general, erm and if, probably a lot of confirmation bias, there's probably a lot of people like me who have gone undiagnosed for a long time or not been diagnosed at all because they do well for themselves, they are a high achiever etcetera and a lot of people experiences of those with autism maybe aren't those people with, you know, successful lives or have difficulties that inhibit daily life.***	Distinction between a clearly defined physical health problem and a "spectrum" condition that is harder to grasp. people's previous experiences with other autistic people may impact how they respond to disclosure/ perceive the autistic person disclosing. Perhaps not meeting their expectation, schema being challenged?
	R: Okay, great, thank you for sharing that. Let's move on to the next question. So I know you sort of said that you do feel indifferent about the experiences but how have the experiences of disclosure affected you?	
	P: **Erm, I think, I think I'm to a degree guarded upon who I decide to disclose to.**	
	R: Okay.	
Cognitive and behavioural impact of disclosure experience	**P: Erm, especially in a, in a professional setting, erm I don't, whilst I know it shouldn't, I don't want disclosure to hinder my progress or how people**	Polarising may not have have an emotional impact, but perhaps more of a cognitive or behavioural impact, as he is more guarded/cautious about

Cautious to avoid discrimination	**treat me at work, erm so yeah, I think there is an element of guardedness involved.** **R: So you feel quite guarded?** **P: Yeah.** **R: But what does that mean to you and how do you feel about it?** **P: Erm, I don't really know, I suppose, you know, cautious. I feel, I don't necessarily feel negatively or positively or more of a, you know, there's a maybe a bit of apprehension to, to figure out who, if or who are the best person to disclose to.**	who he disclose to at work due to the impact it might have on how others treat him and his career. Would disclosing he is autistic meant that he will be held back or not seen as capable? Prejudice and implicit biases

Appendix H

Example of Personal Experiential Statements into Personal Experiential Themes using Conceptual Map in Nvivo




nondisclosure to avoid discrimination
disclosure is context dependent
Avoiding discrmination
hesitant to access services again
reactions impact on how future interactions with others are managed
Preconceptions led to disbelief, lack of support and understanding
but you don't look autistic
lack of support linked to lack of understanding of neurodiversity
disclosure is a process that predates assessment
negative response linked to lack of understanding of neurodiversity
disclosure started pre-diagnosis
receiving support around negative experience of disclosure
being supported through my disclosure experiences
Connection, support, and raising awareness through my lived experience
mutual understanding
connecting and finding community
shared journey, understanding, and posotivity
supporting other with own experience
raising awareness

Appendix I

Tables of Personal Experiential Themes for each participant

Participant 1
Being open about my potential diagnosis Disclosure is a process that predates assessment (15-18, 73-74, 78-84) **Autism is bad news** Lack of knowledge linked to perception of bad news (87-93) Permanence of diagnosis (160-167) Assumption that autism is bad news (169-174) **Masking means I don't fit the preconceptions of autism** Response of shock due to preconceptions of autism (74-84) Masking as an reinforcement of schemas (185-188) Frustration about responses linked to negative schema associated with autism (179-190) **Doubting myself** Autism as a social construct (199-205) Questioning diagnosis during disclosure linked to past trauma (290-305) **Managing awkwardness and deciding who will be interested and understanding** Balancing openness with managing awkwardness (71-74) Response to disclosure depend on the relationship Finding it hard to tell who might be interested compound with theory of mind (91-98) Disclosure is context dependent (29-36) Decision to disclose depend on expected response (87-89) **Am I autistic too** Disclosure lead to self reflection of others (85-86) Person centred as positive, disclose centred as negative (244-253) **Making sense of my life** Sharing diagnosis, feelings of relief, and how it's impact (25-26) Sharing of uncertainty of their feelings about diagnosis (18-24) **Knowledge, openness and being listened to** Appreciation of taking time (244) Appreciation of neutrality and curiosity (227-233, 242-244, 265-267) Response to disclosure depends on knowledge of autism (62-65) Compassionate response and curiosity linked to disclosee's background (219-225) Being taken seriously (242) Response to disclosure depends on disclosure's occupation (67-68) Disclosure's adjusting their response based autistic person's perception (219-225)

Participant 2

Tentative disclosure pre-assessment
Tentative disclosure prior to diagnosis (384-392)

Feeling empowered to change organisation
Empowered by disclosure to create systemic change (271-275)
Empowered to promote system change (440-481)

Social Contagion
Mixed feelings around self-diagnosis due to its impact on those diagnosed (373-377)
Disclosure viewed as an excuse (223-228)
Social contagion fuelling reduced compassion (247-262)

My Autism not believed because of my strength/you don't look autistic
Assumptions focussed on deficit rather than strength aspect (422-433)
Generational differences in response to disclosure (95-106, 225-236)
More skepticism in response to disclosure prior to diagnosis (396-401)
Preconception of autism linked to negative response (82-88)
Response to disclosure depends on knowledge of autism (20-25. 73-79, 95-106, 137-154, 225 -236, 404-420)

Disclosee's denial of their own potential autism
Rejection as a defence mechanism (90-93)

Support understanding and feeling relieved
Relief linked to positive response (20-25)

Becoming myself
Disclosure means dropping the mask and becoming authentic self (39-48)

Not wanting to be labelled
Not wanting to be defined by disclosure (245-249, 296)
Disclosure signifying a change in identity (29-34)
Tentative disclosure prior to diagnosis (384-392)

Building relationships
Navigating disclosure as a social interaction (196-199)
Disclosure as a tool to build connections (251-255)

Being guarded/avoiding discrimination
Seniority as a determinant of workplace disclosure (180-183)
Cautious to avoid discrimination (156-162)
Nondisclosure as default (288-289)
Not disclosing to avoid social complication (172-174)
Decisions are relating to who to disclose to (288-289)

Need for a space to talk about disclosure
Initial discussions and review (324-329)
Summary report for disclosure (335-337)
Lack of support around disclosure (308-309, 332-333, 339-342)
Need for community space (312-319)

Participant 3

Being questioned due to mismatch between preconception and my capabilities
The effects of the age of diagnosis on preconception (41-47)
Confusion due to mismatch in expectation of autism (104-107)
Preconception that autism has a negative impact on work (80-91)

Questioning myself
Questioning as disruption to acceptance (107-109)
Defensive to questioning due to early fragility (95-102)

Handling their emotional reactions
Defending autism and offering reassurance (58-64)

Denial as a defence mechanism
Connotations of disclosure for the disclose about their own identity (55-58)

Nondisclosure to avoid negative reactions
Selective disclosure to avoid negative reactions (184-188)
Nondisclosure to avoid confirmatory bias at work (202-207)

Conflict between becoming more cautious and optimism
Early urge to disclose (171-177)
Worries about preconceptions about enacted (219-226)
Understanding of disability as a factor for disclosure (178-182)
Contemplation to disclose as an act of normalising (207-217)
Potential for disclosure to instil hope and trust (226-233)

Knowledge and lived experience contributing to positive experience
Knowledge and lived experience created norm of positive disclosure experience (191-199)
Progressive view of disability linked to positive experience of disclosure (117-124)

Community, belonging, and hope
Connecting and finding community (151-160, 277-289)
Reassurance and hope through community (280-289)
Sense of belonging (162-167)

Pre-diagnostic disclosure led to support
Expected discussion (14-17)

Neutrality, curiosity, and dropping assumptions made me feel safe and accepted
Worries about change of how the self is perceived by others (139-145)
Immediate disclosure post-diagnosis (20-24)
Expected discussion (14-17)
Openness and dropping assumptions (25-38)
Relief linked to positive response (136-139)
Appreciation of neutrality and curiosity (20-29, 126-130, 136-139)
Feeling accepted and relieved (136-144)

Support to consider reactions and how It impacts me to inform decision to disclose

Post-diagnostic support to consider reactions of disclosure and impact (247-253)
Lack of support around disclosure (238-244)

Participant 4

Tentative disclosure as preparation
Tentative disclosure prior to diagnosis (7-8)

Anxiety in anticipation of disclosure
Nervous about disclosing (93-94)
Anxiety around how to disclose (226-228)

Expressing my needs
Becoming authentic self through disclosure (99-109)
Disclosure to manage stressful situation (191-200)
Disclosure to manage social expectation at the workplace (200-208, 211-220)
Disclosure to manage support needs (211-220)

Developing clearer narratives for disclosure
Considering a narrative for disclosure (123-139)
Thinking about how to disclose (191-208)
Reconsidering method of disclosure (23-26)
Refining disclosure (211-220)

Tools to help others understand
Developing a template for disclosure (257-261)
Need to educate due to double empathy problem (147-158)

Re-evaluating my relationships
Re-evaluating relationships through disclosure (164-167)

Processing my autism and negative responses to disclosure
Feeling isolated (265-269)
Coming to terms with autism and coming to terms with response to disclosure (55-62)
Learning to live with rejection (55-56)

Breaking Stereotypes and driving change
Disclosure as a drive for change in society (182-189)
Disclosure to break Stereotypes (167-187)

Reassurance through connecting with other autistic people
United through experiences (269-274)
Connecting and finding community (151-160, 277-289)

Rejection as a defence to guilt
Rejection as a defence mechanism (55-58)

Not believed due to preconception and masking
Labelled as an imposter (31-35)
Hopes for understanding and change through disclosure (94-99)
Response to disclosure depends on knowledge of autism (9-19)

Preconception of autism linked to negative response (82-88)
Familial traits seen as normal (31-44)
Masking as an reinforcement of schemas (11-19)
Hurt and unsupported (21-22)
Undermined by disclosure (45-49)

Peer support for disclosure
Importance of space to talk about and practice disclosure (278-282)
Informal disclosure discussions through peer support group (247-252)
Support through initial post-diagnostic period and disclosure (285-292)
Lack of support around disclosure (285-286)
Signposting to support network (280-292)

Participant 5

Expected Disclosure
Disclosure as a process that predates assessment (20-23, 62-65)
Initial disclosure to loved one (4-5)
Expected discussion (14-23, 62-65)

Understanding from myself and others
Improved mental health as a result of understanding and support (372-378)
Disclosure as permission to acceptance (272-277, 344-370)
Disclosure to manage social expectation at the workplace (89-117)

Sharing lived experience to help others
Greater purpose (439-447)
Supporting others with own experience (449-459)
Educating others (427-448)
Sharing knowledge as expert by experience (397-415)
Disclosure opening conversations about autism (397-403)

Emotional impact of repeated disclosure
Disappointment in the need for repeated disclosure
Disclosure as a reminder of limitation
Learned helplessness

Nondisclosure as the default linked to lack of change
Non-disclosure when change is not expected (58-60)
Cost and benefit analysis (184-188)
Disclosure to manage relationship (142-145)
Decision to disclose depend on adjustment needs (128-138)
Lack of clarity regarding workplace adjustments (317-335)
Nondisclosure as default (184-188, 282-292)

Support to consider method of disclosure and reactions
Post-diagnostic support to consider reactions of disclosure and impact (493-519)
Informal support for disclosure (479-489)
Own research to support disclosure (492-493)

Participant 6

Managing the emotional impact on others
Managing the emotional impact of disclosure on disclose (22-33)
Balancing openness with managing awkwardness (62-78)

Pre-existing relationship affected response to disclosure
Response to disclosure depend on the relationship (80-95, 343-353)

Feeling unsure
Decision to disclose depend on expected response (354-357, 431-432)

Supported Disclosure for employment
Supported disclosure (357-360, 509-511)

Experience of stigmatisation
Rejection of disclosure in employment context (449-454)

Access to legal protection
Disclosure as a tool to access legal protection (513-517, 521-543)

Openness and changing conceptualisation
Language as a rejection of disorder narrative (177-242, 305-311)
Attitude to disclosure linked to identity (386-397)
Open attitude to disclosure (130-142)
Disclosure is context dependent (145-148, 305-311)
Change in language use through time for disclosure (142-148, 154-168)

Using my lived experience occupationally
Experience of disclosure influenced by organisation culture on neurodiversity (37-384, 454-461)
Continual sharing of lived experiences (398-460)

Participant 7

Negative change in behaviour due to assumptions
Negative change in perception and behaviour (194-208)

Lack of change and understanding
Lack of support linked to lack of understanding of neurodiversity (220-233)
Nondisclosure when change is not expected (171-178)
Systemic constraint to support (279-291)

Avoiding future interactions
Reactions impact on how future interactions with others are managed (210-218)

Becoming more cautious
Becoming more cautious through time (415-422)

Need for self-protection
Nondisclosure as self-protection (113-121, 180-189, 316-318, 342-343)

Private support to consider disclosure strategy
Private support for disclosure (358-361)
Post-diagnostic support to consider reactions of disclosure and impact (365-379)

Letter supporting disclosure
Letter to support disclosure (352-358)

Accessing accommodation and support
Disclosing diagnosis to access support (25-30)
Disclosure to access accommodation (113-121, 327-335, 339-342)

Appreciation of support, adjustments and openness to learning
Feeling accepted and relieved (43-47)
Appreciation of openness to learning (72-84)
Appreciation of adjustment made (90-93)
Anticipatory tension from disclosure (50-57)

Pre-assessment discussions
Disclosure is a process that predates assessment (18-19)

Others' reflection of their own possible autism
Disclosure led to self-reflection of others (18-19, 105-107)

Finding other autistic people
Disclosee's response dependent on their experiences with other autistic people (96-111)

Participant 8

Preconceptions led to disbelief, lack of support and understanding
But you don't look autistic (101-112, 119-121)
Lack of support linked to lack of understanding of neurodiversity (39-48)
Negative response linked to lack of understanding of neurdiversity (17-21)

Avoiding discrimination
Nondisclosure to avoid discrimination (150-168)

Hesitant to access services again
Reactions impact on how future interactions with others are managed (80-87)

Being supported through my disclosure experiences
Receiving support around negative experience of disclosure (223-234)
Shared journey, understanding, and positivity (13-17)

Disclosure started pre-diagnosis
Disclosure is a process that predates assessment (4-10)

Connection, support and raising awareness through my lived experience
Mutual understanding (283-287)
Supporting others with own experience (122-133, 194-200, 283-287)

Raising awareness (186-187, 194-200)
Connecting and finding community (122-134, 171-186)

Participant 9

Disbelief due to mismatch in expectation of autism
Wish to be seen as human before diagnosis (1069-1075))
Mismatch in expectation of autism (27-39, 75-139, 238-256, 310-320)
Disclosee's response dependent on their experiences with others autistic people (147-155, 162-167)

Discrimination and refusal of adjustment
Disclosure being met with discrimination (525-531, 559-570, 921-922)
Rejection of disclosure and refusal of accommodation (366-372, 376-388, 412-422, 448-456, 493-504)

Defence mechanism for identity protection
Defence mechanism for identity protection (189-196)

Dialogue and acceptance through time
Response to disclosure depend on the relationship (261-271)
Rethinking disclosure through negative encounters (177-180)
Disclosee's process of acceptance through time (214-225)

Lack of appropriate support
Lack of post-diagnostic support (730-735)
Support not fit for purpose (757-763)

Need for understanding of neurodiversity and autistic led services
Need for understanding of neurodiversity in society (767-768, 782-783, 790-800)
Need for awareness, welcome, and equal opportunities (846-857)
Need to autistic led services (802-806)

Hesitant to access services
Reactions impact on how future interactions with others are managed (507-514, 522-525)

Increasing visibility and holding others accountable
Disclosure to increase community visibility, promote access and inclusion (643-551)
Disclosure as a tool to access legal protection (618-642)

Participant 10

Disclosure is an extended process
Disclosee's process of acceptance through time (456-468)
Ongoing conversations post-disclosure (336-344, 349-354)
Awareness of potential impact on disclose (471-484, 487-499, 531-564)

Anxiety and overthinking
Partial Disclosure (471-484)

Nondisclosure when accommodation not expected

Nondisclosure influenced by nature of contact (508-516)

Need for resource on how to disclose and dealing with reactions
Therapeutic support for disclosure (199-206)
Navigate disclosure as a social interaction (336-338)
Need for information on experiences of reactions and how to respond (235-242)

Unmasking and accepting myself
Permission to unmask and be myself (63-67, 503-506)
Disclosure as step towards self-acceptance (142-147)

Acceptance and openness
Decision to disclose based on autism characteristics of disclosee (10-20)
Disclosure lead to self-reflection of others (23-31)
Connecting and finding community (23-31, 61-63)
Sense of acceptance (69-85)
Openness being linked to positive disclosure experience (88-94)
Appreciation of neutrality and curiosity (32-38)

Disclosure as activism
Being open to disclosure as a precursor for advocacy (642-647)
Raising awareness (578-590)

Participant 11

Conversation about a possible diagnosis
Disclosure is a process that predates diagnosis (27-39)

Discomfort of others
Disclosee's experience of distress (57-60)
Response to disclosure dependent disclosee's current life circumstances (128-137)

Becoming more selective
Becoming more cautious through time (257-260)
Disclosure is context dependent (257-260, 268-285)

Helping others myself understand my differences
Disclosure led to disclosee's increased understanding of the autistic person (60-61)
Disclosure as a tool to manage social interactions (173-183)

Seeking out information myself
Post-diagnostic resources on pros and cons of disclosure (481-484, 490-491)

Connecting with others with shared experience
Disclosure lead to self-reflection of others (52-57)
Response to disclosure depend on disclosee's characteristics (11-22)
Disclosure opening conversations about autism (185-195)
Positive experiences through shared understanding and autistic identity (11-22, 289-297)
Connecting and finding community (144-150)

Avoidance of discussions on adjustment needs and struggles
Avoidance of adjustment discussions to avoid discrimination (356-369)

Nondisclosure to avoid discrimination (356-360)
Avoidance in talking about struggles (384-406, 493-520)

Not understanding my adjustment needs
Denial of disclosure as avoidance of duty of care (62-106)
Disclosee worrying about getting it wrong (employment context) (212-248)

Balancing activism and my identity
Balancing activism and identity management (150-173)
Empowered to promote system change (507-519)

Participant 12

Pre-assessment disclosure
Disclosure as a process that predates assessment (4-7)

Considering how to approach the conversation
Navigating disclosure as a social interaction (431-442)
Considering different modality of disclosure (463-466)
Disclosure as a reflection of own acceptance (153-165)
Resource of ways disclosing and meaning (469-474)

Dismissing the label
Disclosee's rejection of identity and label
Negative consequence of supportive well intended response

Finding our tribe
Connecting and finding community (169-175)
Positive experience through shared understanding and autistic identity (18-21, 375-378)
Hopes for understanding and change through disclosure (266-267)

Wish for validation and celebration
Wish to be celebrated (457-462)
Wish for validation (71-80)

Imposter syndrome
Imposter syndrome (41-47, 88-117)

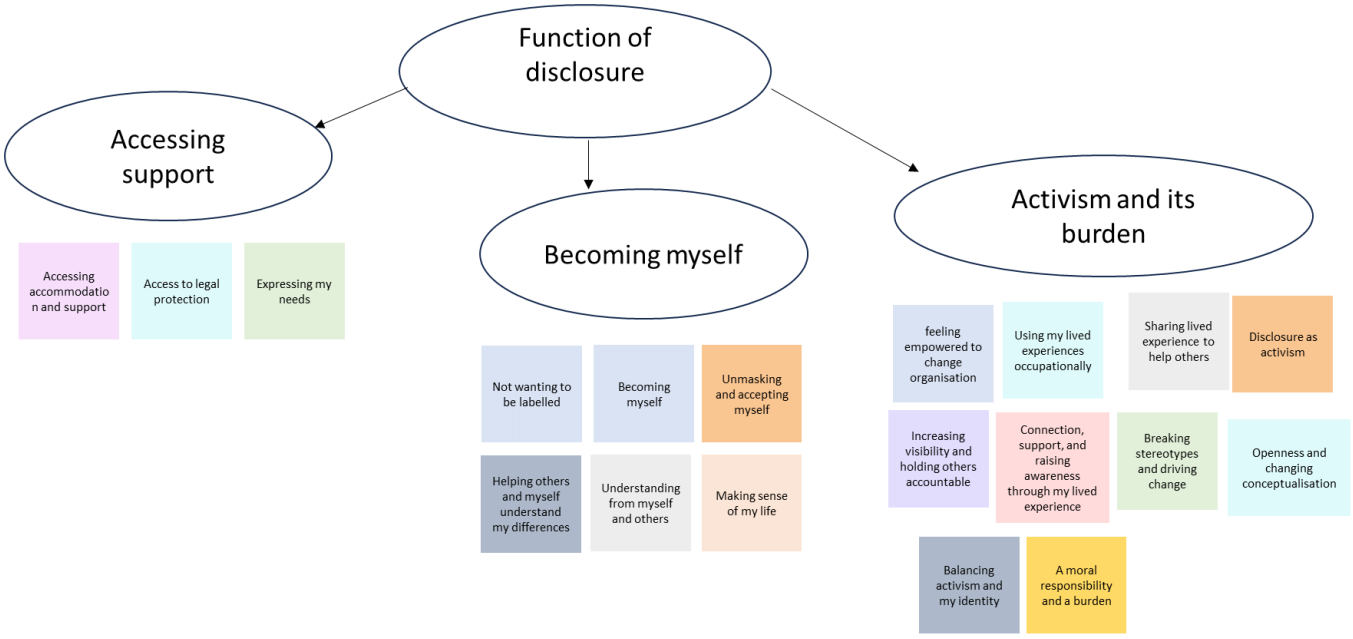
You don't look autistic
Rejection of disclosure linked to preconceptions of autism (391-410)
Preconceptions of autism linked to negative response (276-302)
But you don't look autistic (34-39)

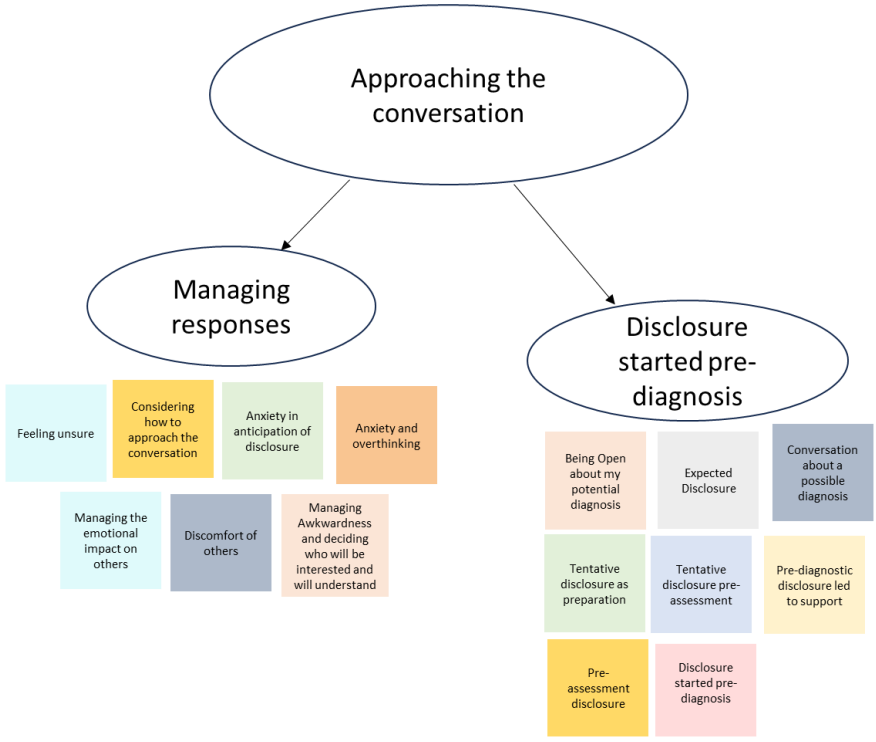
Non-disclosure to avoid negative assumptions
Nondisclosure to avoid negative assumptions (184-216)

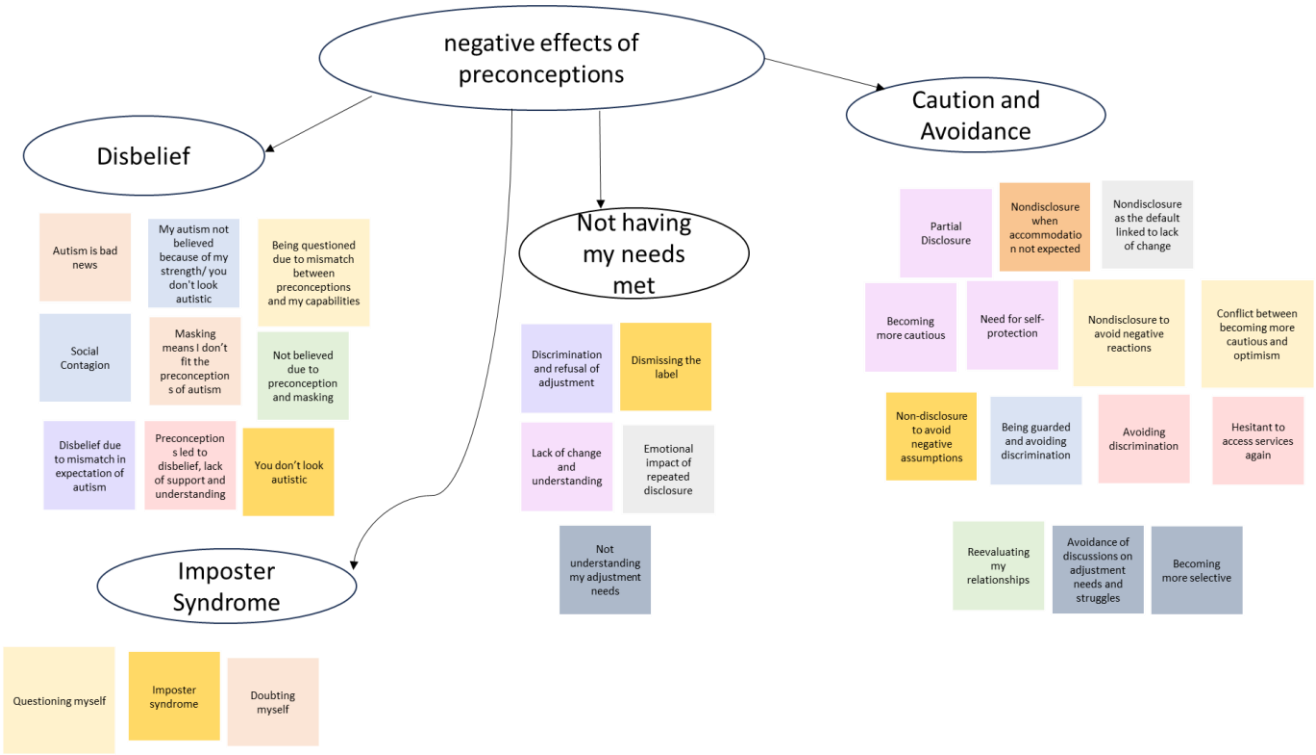
A moral responsibility and a burden
Disclosure as a moral duty (177-181)
Burden of moral duty (323-311, 353-363)
Burden of explaining autism (338-351)

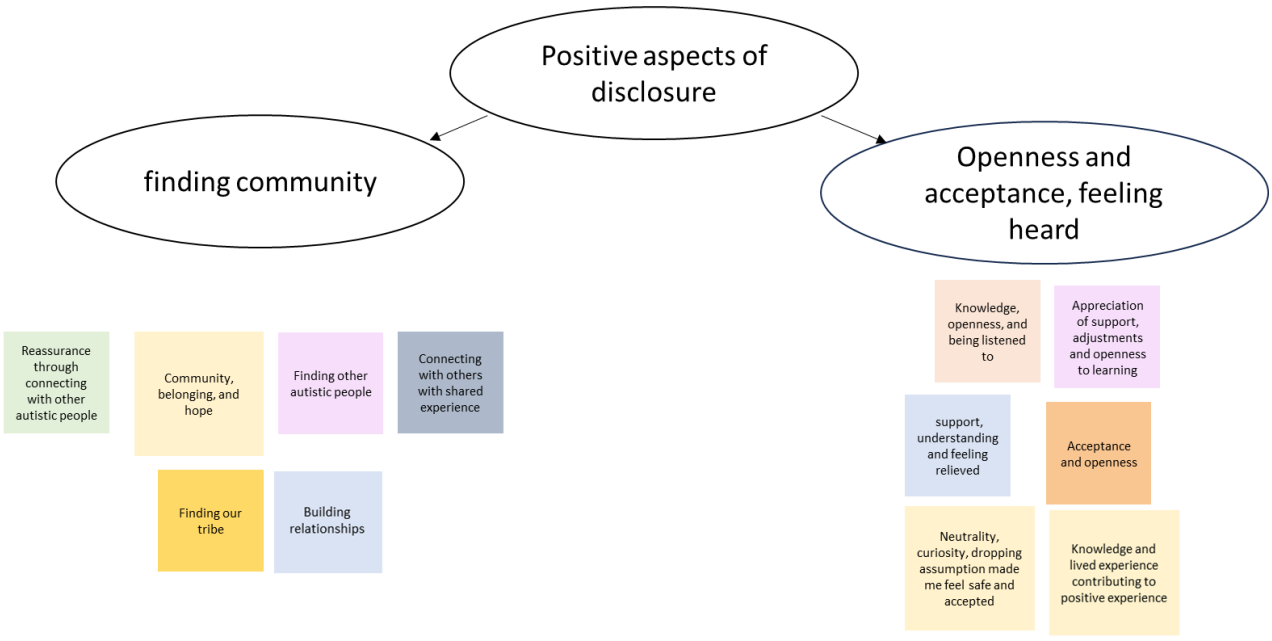
Appendix J

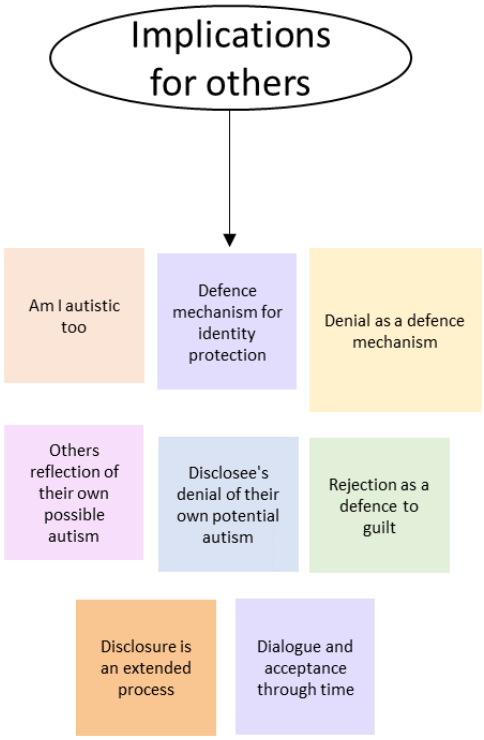
Grouping of Personal Experiential Themes into Group Experiential Themes
Note. Each colour presents a unique participant

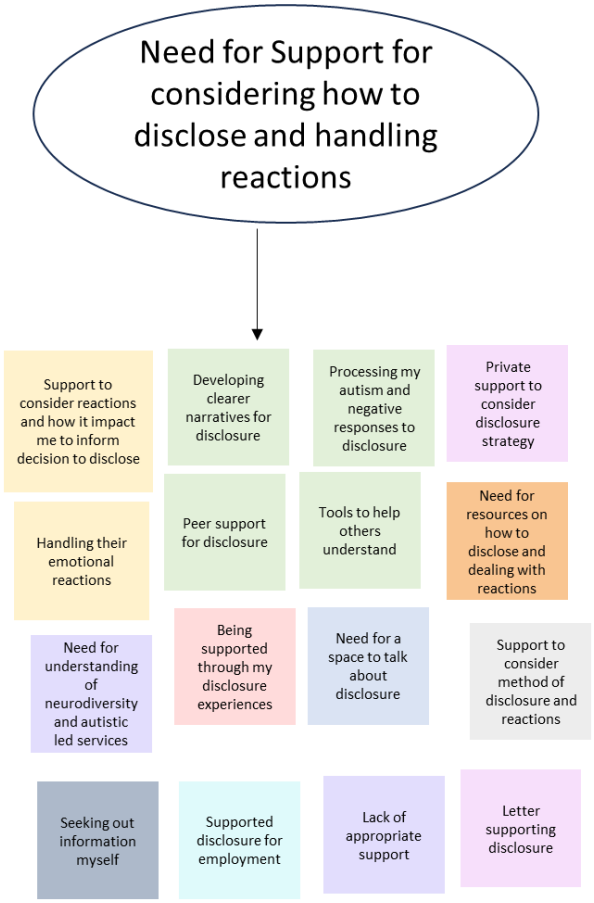





negative effects of preconceptions
Disbelief
Autism is bad news
My autism not believed because of my strength/ you don't look autistic
Being questioned due to mismatch between preconceptions and my capabilities
Social Contagion
Masking means I don't fit the preconception s of autism
Not believed due to preconception and masking
Disbelief due to mismatch in expectation of autism
Preconception s led to disbelief, lack of support and understanding
You don't look autistic
Not having my needs met
Discrimination and refusal of adjustment
Dismissing the label
Lack of change and understanding
Emotional impact of repeated disclosure
Not understanding my adjustment needs
Caution and Avoidance
Partial Disclosure
Nondisclosure when accommodatio n not expected
Nondisclosure as the default linked to lack of change
Becoming more cautious
Need for self-protection
Nondisclosure to avoid negative reactions
Conflict between becoming more cautious and optimism
Non-disclosure to avoid negative assumptions
Being guarded and avoiding discrimination
Avoiding discrimination
Hesitant to access services again
Reevaluating my relationships
Avoidance of discussions on adjustment needs and struggles
Becoming more selective
Imposter Syndrome
Questioning myself
Imposter syndrome
Doubting myself


Positive aspects of disclosure
finding community
Reassurance through connecting with other autistic people
Community, belonging, and hope
Finding other autistic people
Connecting with others with shared experience
Finding our tribe
Building relationships
Openness and acceptance, feeling heard
Knowledge, openness, and being listened to
Appreciation of support, adjustments and openness to learning
support, understanding and feeling relieved
Acceptance and openness
Neutrality, curiosity, dropping assumption made me feel safe and accepted
Knowledge and lived experience contributing to positive experience


Implications for others
Am I autistic too
Defence mechanism for identity protection
Denial as a defence mechanism
Others reflection of their own possible autism
Disclosee's denial of their own potential autism
Rejection as a defence to guilt
Disclosure is an extended process
Dialogue and acceptance through time


Need for Support for considering how to disclose and handling reactions
Support to consider reactions and how it impact me to inform decision to disclose
Developing clearer narratives for disclosure
Processing my autism and negative responses to disclosure
Private support to consider disclosure strategy
Handling their emotional reactions
Peer support for disclosure
Tools to help others understand
Need for resources on how to disclose and dealing with reactions
Need for understanding of neurodiversity and autistic led services
Being supported through my disclosure experiences
Need for a space to talk about disclosure
Support to consider method of disclosure and reactions
Seeking out information myself
Supported disclosure for employment
Lack of appropriate support
Letter supporting disclosure

Appendix K

Audit form completed by research supervisor

Audit Checklist

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?
Yes/Partially/No (As evidenced by anonymised transcripts/photo-elicitation/data etc)

Yes, I have seen all redacted transcripts

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?
Yes/Partially/No

Yes, I have seen the relevant excel file

3. Are there reflections/notes/summaries on the data collection process?
Yes/Partially/No

Yes, I have seen the reflective diary and Sheena read extracts during a supervision meeting

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?
Yes/Partially/No

Yes, all recorded on PATS

5. Has the data been sufficiently coded? (e.g., is all the relevant data coded?)
Yes/Partially/No

Nvivo files shared and can view evidence of comprehensive coding CHECK

6. Has the data been systematically coded?
Yes/Partially/No

Spot check on Nvivo CHECK

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified?

(This may be evidenced by looking at different versions of documents and notes, and changes to coding/themes should be justified).
Yes/Partially/No

Documented on excel files CHECK

Evidence shared on NVivo

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded.

Are these consistent?
Yes/Partially/No

I asked to see Ppt 6 on NVivo and saw the descriptive, conceptual and linguistic codes

9. Vice-versa crosschecking randomly selected themes and subthemes against the corresponding data.
Are these consistent?
Yes/Partially/No

I asked to see Ppt 5 conceptual map and saw data corresponding to the participant experiential themes

Study write-up/results
10.Are quotes sufficient to provide evidence of the themes and subthemes?
Yes/Partially/No

I saw how the quotes linked to the participant experiential statements and how these linked in to the PETs

11.Does the results/write-up sufficiently address the aims of the study?
Yes/Partially/No

Yes, the results address the aims of the study

Appendix L
Additional Supporting Quotes

Group Experiential themes	Group level Subthemes	Additional quotes
Functions of Disclosure	Accessing support	I was on the phone call, I was having to reports something to the police, a crime to the police. So I got, I got sort of, erm so yeah, start getting brain fog and, yeah, feel like I lose the ability to speak, so, sort of stop myself and say, “Sorry, I'm, I'm autistic, so I can get, so, I can get like this.” So, erm so, yeah, so I can I feel I can disclose *(Jane)*
		because one of the things that I wanted to get the diagnosis for was to get to get support. Without the diagnosis, you don't get things like social service support and all the kind of benefits that you need because you tell them your symptoms but they don't believe you. They tell you “what you can’t" because I've got erm I've got PDA diagnosis as well, but I just think that's part of autism, get over-whelmed, you can't do stuff. (Tina)
	Becoming myself	it was almost like being seen for the first time, being sort of truly seen for the first time (Josh)
		Yeah, I don't know. I I don't socialize with work colleagues. You know, and I used to um because I thought it was expected and so on, whereas these days, I unless I absolutely have to. I don't. So for example, you know, there's an annual dinner with the trustees which is supposed to be entirely social. Well, I'm a senior manager, I kind of have to go, that kind of thing. Yeah, alright, I'll just, this is work, definitely work. It's, you know, that's fine. But if I've got a choice about, you know, so I know there's a lot of my colleagues who I work with every day we're going out for a drink tonight, I have no interest in going to that whatsoever [laugh] be you know, just does not appeal and, but yeah, and I suppose these days I'm able to go, “Yeah I'm not interested. Thanks that's fine. Go have a great time. No problem with that. But no, I'm not going.” (Brandon)
	Activism and its burden	“And I I'm really on the fence about it because I'm the one hand, I feel like well you know, if I'm gonna see someone again, why on earth should they should I

		tell them anything else about me? But there's another part of me that you know, my therapist has said very specifically to me, “[name of participant], you are not now responsible for all the autistic people”, but there's a part of me that almost wants to do it for political reasons, almost like it as an activist almost, you know, to advocate as an autistic person to say to as many people as I possibly can almost as a broadcast. “I'm autistic person. If you didn't know what autistic person looks like, or, you know, acts like. then I am one, you've known me for probably quite a few years. And please ask me any questions.” So yeah, there's a part of me that really thinks, Yes, it is really important to disclose, because you're you know, you're helping the autistic community, particularly autistic women because I think it's so misunderstood in women.” (Rachel)
		P: Yeah, I guess because I started accessing the support service before my diagnosis. just felt very comfortable, speaking to the other neurodiverse people about, You know how I felt all the time and the condition that I know I have now. so, yeah, I think it's just, just kind of yeah, kind of raising awareness and you know, just just seeing how people are, and certainly within the people that I meet at work, both my colleagues and, you know, the clients it’s, we just kind of always understand each other, basically, (Edward)
		I kind of really struggled because what actually happened was, and I've experiences in other ways as well, I suppose different compartments coming together. so, so I was there in my, you know, the version of myself that is goes to autism dialogue sessions, but there are people attending the conference who know me in my work capacity, and I found that really challenging. To have those two two brought together. (Brandon)
Approaching the Conversation	Managing disclosure and responses	
		yeah, I think so because I, with my dad, I think I was beating around the bush a bit because I was sort of saying. “Have you heard of neuro… there's something called neurodivergence” and I wasn't really like, you know, personalizing it in any way um you know, I suppose I didn't really know how to go about it. I didn't know how he was gonna react and he's sort of been left now. He knows that my son's been diagnosed autistic and he's being quite good about that. He's been understanding and he's asked what that will mean for him as an adult. But what I haven't ever done is done that, is just say to him, “I'm autistic and I have got a diagnosis and I know that this is the case, and it does run in families.[laugh] So you might want to read about it.” I've never done that. So, um and I think he's now sort left thinking, oh, you know, “something about neurodivergence, don't really know what it is, I don't really know what she's talking about. I don't really know what she means”. and he won't ask, because you know, he's just wouldn’t, he just wouldn't sort of go there, so I think I need to maybe make it clearer to him.

		(Rachel)
		…I guess even at at home, you know, some tensions and some friction that there was growing up, you know, being being at home so I felt a little awkward because I didn't want my parents to feel that they had erm that they… what's, what's the word I'm looking for… that they hadn't supported me that they had that they had, Um, sorry, I'm hunting for the correct word, that they had gosh sorry. Sorry [researcher's name'. (Eric)
		I think I said about my assessment first and not long after her child was was diagnosed autistic. Um, you know, and had all sorts of eating issues, and mental health issues, and really, really unwell as a teenager, and so since then really in particularly around my father's death that my sister's just dropped out of contact altogether with me. Um you know, I think it's one of those things where I think, I've sort of opened a kind of worms for he, and which is a bit of a repeated pattern between us. (Brandon)
	Disclosure started pre-diagnosis	"Erm, I told my mum but because of doing the questionnaire together, erm again we were pretty certain that that's what it was gonna be, there weren't any surprises around". (Michael)
		The only person that I have conversations with on the approach to, erm was my wife, possibly NAME because she works in this sector and maybe my mother just to say, you know, "I'm going through this process" but undetermined, you know, I wouldn't even say I might be autistic, its erm "I'm going through a process because there's a few signs to say that I could be but then in turn I could just have the traits of someone that is autistic, that doesn't necessarily mean I am", so I was quite, I suppose I was almost guarded going through the process as well because I didn't want to, I suppose I didn't want to label myself before being labelled again (LAUGH). (Josh)
Negative Effects of Preconceptions	Disbelief	It was an online one and I said to the trainer, you know, in the introduction part,, you know, I'm autistic and I work for the [local neurodiversity support service] and I think he kind of just expected that there was some kind of, implication, that autism always came with learning, you know, problems. R: Right. P: And I think some people kind of expect to kind of a look at the kind of different. Oh, you don't look autistic, you know, that kind of thing. R: And what do you think about that? P: Well, I know from my own work, you know. Yeah. There's people that I think probably those that really have some learning difficulties that, have a slightly different look, kind of kind of a blank expression I suppose. And those that are kind of on the Aspergers or high functioning and that don't have, I (Edward)

	P: So he kind of like just shrugged it off really. He was like “okay that's yeah, whatever.” And I told another friend who is autistic or he, he was diagnosed quite a long time ago, so he would identify by saying that he has Aspergers and… R: Right. P: he, I thought that he was going to be positive. But he was like, Oh, but you don't seem autistic. (Liza)
	P: And I'm very good at masking. but then I, so I I know why. the friend said, you know, “you don't seem autistic” because I think I've had, at that point like 38 years or 40 years of knowing how to behave or how to present. (Liza)
Imposter Syndrome	so I get it, but I also think that people don't realise like how disruptive that question can be to people who have only just really come to terms with the diagnosis themselves. (Olivia)
	P: So, I think he meant well, I think he was just kind of surprised but it's I think it threw me a little bit. R: Right. P: because I think I had quite a bit of an imposter syndrome of like, “oh, am I really or was I just faking” or you know, like those kind of thoughts? and I think he him saying that kind of made me feel a little bit like, “oh, what if I'm what if I'm not”, you know, so (Liza)
Not having my needs met	“frequently I’d like to be able to book a double length of time, I struggle with articulating myself under pressure…. I ring my GP up and I say “can I have a double thing, you know I’m autistic”, and they’re like “no, no, that’s by prior arrangement, if you had a carer they could do that or if your doctor said that you needed that you can do that but you can’t ask for that”, and it’s crazy because when I get into the doctors they are like ‘oh you could do with like an extra five or ten minutes just to have this conversation’, but I can never get it cos no one is willing to make that accommodation for me because I don’t have a designated carer because why would I (LAUGH).” (Jess)
	“they didn't seem to understand that neurodiversity can also be debilitating, and they and the DWP, basically rang the first working day after I've got my diagnosis. And because I was wondering whether I could have adhoc help with certain things. erm, where you know I was saying I have trouble showering. Now, the only trouble they know of with showering is physical disability. ‘Oh yes, we can have somebody come into your house.’ I don’t need somebody! … They just didn't understand that it again, it was a negative reaction of all, you know,’ why would you need us if you don't have a physical disability?’ So the services aren't really aren't there. (Tina)
	I suppose it annoys me a little bit that, that that’s, that that’s the case having to

	keep telling people, erm (SIGH), I don't know if there's anything more around that to say. I can't, I obviously can't control what people do, think, remember, erm yeah its, and I suppose sometimes it gets to a point where I think I will just not bother telling, I'll just not bother reminding them, I will just try and muddle along and not remind them because it just feels, it, I suppose it does feel quite an effort sometimes to do that, erm yeah, I don't think there is anything more really I've got around that. (Michael)
Caution and avoidance	Yeah. Well but yeah, I will… most people I don't mind them knowing but, it's, at first I think I did disclose too often. Um I was just telling everybody. um "hey bin man. Hi I'm autistic you know?" [laugh] I didn't actually do with with the bin people, but it was a bit like that. Telling it all to just about everybody. Now I'm I think I'm more cautious about it. It's a "well, do they need to know?" No they don't, on we move. But I do find it useful to use to really ask for help with people. And even if they don't understand it, they know that it's something that they might need to pay attention to if that makes sense. Um (Tina)
	yeah, I think if I was applying for a job that wasn't in like the autism sector. I don't think I would. R: Right. P: Erm, there was…[sigh] Yeah, there was, I was just thinking that there was something recently and so it was for like bereavement support. R: Okay. P: that I think that they were kind of like, is there anything else that I need to know and I had a moment of thinking should I tell them that I'm autistic because It might affect, that I, you know, like maybe I don't understand things clearly or that that I process things differently and stuff, I know, but I thought, no because then they might make assumptions about me (Liza)
Impact on others	Yeah my dad definitely does not believe that I'm autistic, erm I feel like that might be an element of doubt because everybody says that me and my father are so much alike, so I almost wonder is there a fear there that he thinks "well, maybe I'm also autistic" and wants to deny that on that basis. (Josh)
	it erm then they get it and I think with my family like with my mum there might, there might have been a bit of guilt on her behalf that she never picked up on it erm she never noticed it, that I would I had struggle well I struggled through my life with it so she you know as a mother I can understand she might be upset about that part erm, yes, so I think I what I've understood is it, it comes from the individual's viewpoint and also stuff, baggage, that they're carrying themselves as well, so that influences (Jane)
	I think that's the problem, the disclosure sort of situation is very pressured because you're feeling like, you should say, the right thing and the other person's

		feeling like they should say the right thing, but it's weeks, months, after that, that I think the proper, you know, the real conversations I had. And I think that's where I'm getting to with my mum now is, you know, it'll just be something we're talking about something completely different. and then autism, will just come in from somewhere, and then, and then she'll ask a question about it, and then I'll feel comfortable to answer. So, That feels like the real disclosure. I think, you know, the conversations that come latterly (Rachel)
Positive aspects of disclosure	Acceptance and understanding	but her response, I quite liked it because she took me seriously, and it wasn't, there was no assumption that it was bad news, it was quite neutral, erm yeah and she took the time, like she was interested and that's quite nice (Helen)
		P: So it was different in that we were both open and comfortable with each other. Yeah, rather than I think, when it's somebody who's known you for a long time and you're telling them and you feel a bit like what you're saying, particularly, when you're trying to explain masking that's really, really hard, because you know, the other person might think, "Well, have you been lying to me, then", you know, and it's not that you've been consciously trying to, you know, sort of be disingenuous or anything. It's, you know, it I think, I think for a long time I just thought I'm just a bit shy and I just need to sort of pretend to be more confident. I suppose that's the way to describe how the masking appears, and so yeah, so it was it was it was just nice to feel that she just accepted me. That was it. It was complete acceptance. There was no sort of doubt. There was no questioning. There was no. "Well, what do you mean by that?" Because that's that's what I usually get is "Well, what? What does that mean? And then you feel like you sort of under pressure to try and explain the whole idea of, you know, what an autistic person is and what you know and and it's just overwhelming. Whereas with her it didn't feel overwhelming. It felt almost sort of exciting, you know, to be able to have a nice positive conversation that flowed and was two way. So it wasn't like you know, the other person just asking (Rachel)
	Finding community	I'm very lucky that way. It turns out, I've got two friends, neither of whom I've seen in a couple of years, and they're both autistic, too. We autistic people don't know if you know this, autistic people, we tend to recognise each other, we might not realise we're autistic, but we click instantly. I've had it happen a few times and then later found out that person is autistic. So yeah, they're both turned out to be as well even my pen pals is autistic. R: Wow. So what was what was it like to, I guess. And if you have shared your diagnosis with them, what was it like for you to share? P: And with, with [friend], he can't talk on the phone much, so we usually correspond by messages and facebook. And, and he was absolutely fine about it, and he subsequently discovered that he was as well. Don't know if he's

		officially diagnosed. Erm [another friend], her nephew was autistic. And, and she, somebody sometime [inaudible] my diagnosis actually, you said I bet you are as well. When she's when she got to thinking about and looking at it. Yeah Okay. So she was she was obviously fine with me being autistic. She's used to dealing with an autistic person. (Tina) R: What was it like for you? P: Yeah, I think it was It was slightly nerve-wracking, but like you know a lot of friends know and I've had conversations with a lot of friends who like we think that we all just existing in quite a neurodiverse bubble. So we're all probably either autistic or have ADHD or, you know, so like we found our tribe. So they are very, very accepting bunch and a lot of people know that like I work with autistic people, I'm a study skills tutor for autistic uni students. (Liza)
Need for Support for considering how to disclose and handling reactions	-	"yeah, I think it I think it would have been useful just to have a bit of time to consider how might different people react, how might that make me feel. And I think if I'd have that opportunity to go through it with someone who's, who's known a lot of autistic people who have disclosed, then I think maybe I could have anticipated some of them negative stuff and then made more informed decision about whether I actually want to disclosed." (Olivia) P: So, yeah, I mean talking before I started working for [local neurodiversity support service] obviously, I had the support of those people that are now colleagues and the other people that came along and, you know, I was, it was quite difficult. It wasn't difficult talking to them about my experiences with my sister and earlier times with my parents, because, you know, I think everyone or most people have experienced this difficulty in lack of understanding, you know, when they're talking to family or friends, you know, some people just get it and some people really don't R: Right. And what do you think about that support that you've got? And is there anything that you would like to change? P: um no, not really no. R: So that sounds like it's quite helpful. P: Very much so. Yeah. Yeah. (Edward) Erm, yeah I suppose, I suppose I would. I think, (SIGH) potentially, it probably wouldn't work for most autistic people but maybe remotely would do but you know, I feel like almost group sessions would be helpful, you know a space to be able to discuss, it almost seems like I'm talking about an AA meeting here but a space to discuss experiences with learning about your autism, with how you deal with life as an autistic person and you know, experience of disclosing as, as an autistic person, I think that sort of a community/base to be able to talk about it

would be good. (Josh)