Improvement in anxiety, depression, and/ or related emotional difficulties in autistic adults

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part one is a systematic review examining the literature on individuals who are initially diagnosed with autism but no longer meet the criteria at a later stage when reassessed. It considers the findings in relation to a set of hypotheses as to the nature of this: (1) deficit-recovery model, (2) false positive hypothesis, (3) false negative compensation hypothesis, (4) continuum hypothesis. Links to psychological well-being are discussed.

Part two is a qualitative empirical study exploring 15 autistic adults' lived experiences of improvements in depression, anxiety and/ or related emotional difficulties. This is in recognition that autistic people experience a range of related emotional concepts such as masking, burnout, meltdowns, and social camouflaging, which may not be captured by existing mental health measures. Semi-structured interviews were conducted, and four overarching themes identified: personal factors, interpersonal factors, environmental factors, and strategies/ support. Implications and suggestions for future research are considered.

Part three is a critical appraisal of the research process. This includes further reflections on ethical considerations including the role of a non-autistic researcher, accessibility, collaboration with experts by experience, language sensitivity, methodological decisions, and the value of the research across different domains, including personal and professional impact.

Impact Statement

This thesis explores key issues in relation to autistic mental health, addressing a crucial gap in clinical and academic settings.

The systematic review highlights the impact of masking or compensatory behaviours, which are not recognised by diagnostic criteria. Importantly, these individuals continue to face significant challenges related to mental health, underscoring the profound impact of undiagnosed or misdiagnosed autism on well-being. The findings advocate for a paradigm shift towards recognising autism as a lifelong neurodiverse profile, urging clinicians and researchers to adopt more nuanced and multi-modal diagnostic frameworks.

In the empirical study, qualitative interviews illustrate the lived experience of autistic adults' improvements in their mental health. Lived experience research is valuable because it provides authentic, first-hand perspectives that increase understanding and inform more empathetic and effective interventions and policies.

Both parts highlight that improvements in autistic mental health are associated with a greater acceptance of autistic identity and reduced pressure to conform. There are a number of implications for clinical practice involving neuroaffirmative approaches, suggesting that interventions should prioritise accommodating diverse cognitive styles rather than suppressing autistic traits.

The impact of this research extends beyond academia, advocating for policy changes and societal awareness that uphold the rights and dignity of autistic individuals. It highlights the importance of considering autism within an ecological model that creates a more inclusive environment, allowing autistic people to thrive.

Table of Contents

List of Tables and Figures

Systematic Literature Review

Empirical Paper

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Part 1: Literature Review

Characteristics and outcomes associated with individuals who no longer meet the criteria for an autism diagnosis: a systematic review

Abstract

Aims: Research has identified a subgroup of individuals who were initially diagnosed as autistic but who no longer meet the diagnostic criteria for autism upon later reassessment. This review aims to provide a comprehensive overview of what the literature informs us about this population, including cognitive, behavioural, and psychological characteristics, as well as co-occurring outcomes.

Method: A systematic literature review was conducted using the databases PsycINFO, Medline, Scopus, and Web of Science. Following screening and data extraction procedures, a total of 29 studies met inclusion criteria and were synthesised for review.

Results: Of the 29 studies included, 15 studies identified a higher presence of autistic traits in the loss of autism diagnosis (LAD) group compared to typically developing (TD) but lower than autistic (ASC) comparison groups. Nine studies did not identify any significant differences between LAD and TD groups. Five studies did not compare groups but aimed to characterise the LAD samples. Masking, compensatory mechanisms and negative psychological outcomes were identified.

Conclusion: The findings lend support to several hypotheses for LAD: 1) false-positive hypothesis (incorrect diagnosis, later corrected; 2) false-negative hypothesis (autism unrecognised during reassessment due to compensatory/ masking behaviours); 3) continuum hypothesis (autism as a spectrum in which individuals move above or below threshold at various points in time). All of the above are consistent with a lifelong, neuroaffirmative understanding of autism. In consideration of the limitations of current diagnostic practice, implications for future research and practice are discussed.

Introduction

Autism (autism spectrum disorder) is a lifelong neurodevelopmental diagnosis that encompasses differences in communication, social interaction, and restricted or repetitive behaviours (DSM-5, American Psychiatric Association, 2013). Prevalence studies estimate that as of 2018, 0.82% of the population in England may have been formally diagnosed as autistic, with a further 0.77% - 2.12% of the English population who may be autistic and remain undiagnosed (O'Nions et al., 2023). Similarly, global prevalence studies estimate around 1% of the population may identify as autistic (Zeidan et al., 2022).

Historical Evolution of Autism Diagnosis

Conceptualisation of autism has evolved over time. First described as Kanner's syndrome, also known as 'early infantile autism', autism was defined as a specific 'pattern of abnormal behaviour' (Kanner, 1943, as cited in Harris, 2018). There was later recognition of a group of children who did not fully meet the criteria for Kanner's syndrome, but displayed a 'triad of impairment in communication, social interaction, and imagination' (Wing & Gould,1979). These children were described as being "on the broader autism spectrum", hence autism becoming conceptualised as a spectrum. Later diagnostic criteria introduced 'Asperger syndrome', a subgroup of individuals who held autistic traits but had language and grammatical abilities in the average to superior range. This is no longer officially used as a diagnostic term with the publication of the DSM-5 in 2013 (American Psychiatric Association, 2013), which merged Asperger syndrome with the diagnosis of 'autism spectrum disorder'.

Shift from Deficit Model of Autism

As is evident from the historical diagnoses, autism has long been viewed through a deficit model lens, emphasising the impairments and challenges faced by individuals who identify as autistic. However, current autism research is increasingly informed by a neurodiversity perspective, which recognises neurological differences (including autism, ADHD and other neurodevelopmental conditions) as natural variations within the human population. This paradigm shift reframes autism, rather than as a set of deficits, instead as a unique cognitive profile with advantages and strengths as well as difficulties (Dwyer, 2022; Kapp et al., 2013). In light of a neurodiversity perspective on autism, it has become viewed as a lifelong identity, rather than a set of deficits to be overcome. A second shift is that through an ecological model, the challenges faced by autistic people are no longer viewed as arising from a pathology within the individual, but rather from a dynamic interaction between an autistic individual and (often poorly adapted) environments, also known as the person-environment fit model (Mandy, 2023).

‘Loss of Autism Diagnosis’ (LAD) Subgroup

Despite the paradigm shift in the autism field, there has emerged in the literature a subgroup of individuals who initially meet the criteria for autism, but upon reassessment at a later stage no longer meet the diagnostic criteria, commonly referred to as achieving "optimal outcomes”. In recognition of the neurodiversity approach endorsed by the autism community, this review will not refer to these individuals as having achieved ‘optimal outcomes’ and will instead refer to them as ‘Loss of Autism Diagnosis’ or LAD individuals. This is because it is not assumed that reduced measurements of autistic traits are inherently helpful.

Historically, it was assumed that individuals could be considered 'recovered' from autism once certain deficits were overcome. However, this review aims to explore a range of possible explanations for a loss of autism diagnosis, without assuming that this necessarily equates to an optimal (or positive) outcome for the person. Possible hypotheses as to the nature behind loss of autism diagnosis are outlined below:

1) With “treatment”, some people “recover” from autism (This is the historical, deficit-recovery hypothesis)
2) There are routinely people who are misdiagnosed as autistic in childhood, whose diagnosis can be corrected later (false positive hypothesis)
3) There are routinely people who are correctly diagnosed autistic in childhood, who would be incorrectly not given the diagnoses later (false negative - compensation hypothesis)
4) Autism should not be understood only as a categorical phenomenon, but also as a continuum, with some people showing higher than average autistic traits and passing above and below diagnostic thresholds at various points in time (continuum hypothesis)
5) A combination of some or all of 2-4.

Diagnostic Process

Two tests that are gold standard tools of autism assessment are the Autism Diagnostic Observation Schedule, Second Edition (ADOS, Lord et al., 2012) which involves a semi-structured set of observations, and series of activities involving the individual and a trained examiner, alongside the Autism Diagnostic Interview Revised (ADI-R) which involves a structured interview usually completed with a caregiver to gather information about developmental history and autistic traits (NICE, 2021). It

should be noted, however, that there have been criticisms of such measures in the literature for several reasons, for example queries of limitations in sensitivity and specificity (Kaufman, 2020). It is also important that clinicians should use the standardised diagnosed instruments as a tool to aid clinical judgement in the process of gathering neurodevelopmental information rather than as a ‘definitive’ answer, and this should be with populations they are validated for (Bishop and Lord, 2023).

Masking Behaviours

Diagnostic assessment can be directly impacted by ‘masking’ or ‘camouflaging’ behaviours. This refers to the conscious or unconscious effort by individuals to conceal their autistic traits in social situations. A systematic literature review identified that autistic individuals who engage in behaviour to pass as neurotypical are by definition more likely to appear non-autistic and therefore may fail to be referred for diagnostic services and/or fail to meet full diagnostic criteria for a formal ASD diagnosis (Libsack et al., 2021). Research suggests that masking is a highly prevalent behaviour that often comes at great personal cost to wellbeing by causing significant emotional and mental strain, leading to increased anxiety, depression and burnout (Miller, Rees & Pearson, 2021; Cook, Hull, Crane & Mandy, 2021). Furthermore, interventions such as Applied Behaviour Analysis (ABA), which is commonly utilised with autistic children, may inadvertently reinforce masking behaviours, potentially influencing the likelihood of individuals altering their behaviour in a way that means they no longer meet the criteria for an autism diagnosis. The presence of higher levels of secondary negative psychological outcomes in the LAD group may lend some support to the idea of a false-negative diagnosis due to autistic masking.

Rationale for Review

This review aims to:

1) Systematically explore the existing evidence base on LAD individuals.

2) Better understand the characteristics and outcomes associated with the loss of an autism diagnosis.

3) From this information, investigate evidence which supports or contradicts the numbered hypotheses on the nature of LAD (as outlined above)

4) Given what is known about masking and camouflaging behaviours, the review seeks to gain insight on the implications of no longer meeting the diagnostic criteria of autism for these individuals, including outstanding needs.

5) Finally, with this further insight, the review aims to add to the evidence base that informs support systems and interventions that best serve autistic individuals within the context of neurodiversity,

Method

This systematic review was performed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines (PRISMA; Page et al., 2021). Methods were predetermined in a protocol submitted to the PROSPERO database of systematic reviews (PROSPERO CRD42024458581; Limby-Wauchope, Pender, & Mandy, 2024). This systematic review involved a comprehensive search across multiple databases, including PsycINFO, Embase, Medline, and Scopus. Searches of databases occurred between November 2023 to February 2024. EndNote 20 Software was used to manage references and document progress.

Search Strategy

To identify appropriate search terms, relevant published papers were reviewed, and relevant synonyms or keywords collated. A search strategy was developed with appropriate truncation (Table 1). Search terms relating to each of “autism” and to “loss of diagnosis” were combined using the Boolean operator “OR”, and then these groups were combined using the Boolean operator “AND”. The search term ‘autism spectrum disorder’ was exploded to maximise identification of relevant studies.

Table 1 Search Terms

Domain	Search Term
Autism	autis* or ASD or ASC or Asperger* or Kanner* or PDD* or pervasive adj2 development
Loss of diagnosis	optimal adj2 outcome* or loss adj3 diagnos* or lost adj3 diagnos* or reduction adj3 autis* or below adj2 autis* or remission adj2 autis* or recover* adj2 autis* outgr* autis* or previous* adj3 autis* or history adj2 autis* or history adj2 ASD or history adj2 ASC

Eligibility Criteria

To be included in the review, studies were required to meet the following criteria.

Inclusion criteria:

1) Studies involving adult, human participants

2) A clinical or research diagnosis of autism

3) LAD participants include those who no longer met the diagnostic criteria upon reassessment

4) Quantitative studies

5) Diagnostic assessment involves the use of standardised measures that are considered gold-standard, i.e. the ADOS and ADI

As the study is interested in a broad range of outcomes, there was no specification on the type of outcomes reported. The decision was made for the inclusion of individual case studies and non-peer-reviewed studies in acknowledgement of the heterogeneity of the autistic population and in hopes to capture diverse experiences and outcomes.

Exclusion criteria:

1) Studies in which participants self-identified as autistic without formal diagnosis
2) Studies that are not accessible in English Language
3) Qualitative studies that do not allow for comparison of outcomes/ traits
4) Studies published prior to 1994 (the introduction of the DSM-4 criteria for autism diagnosis)

It is recognised that many autistic individuals prefer to self-identify rather than seek a formal/ professional autism diagnosis (Sarrett, 2016), however, ensuring as much as possible that the same standardised diagnostic criteria were applied at initial and re-assessment helps to ensure validity in the case of this review. A clinical or research diagnosis is more likely to reflect the DSM or ICD diagnostic criteria. Self-

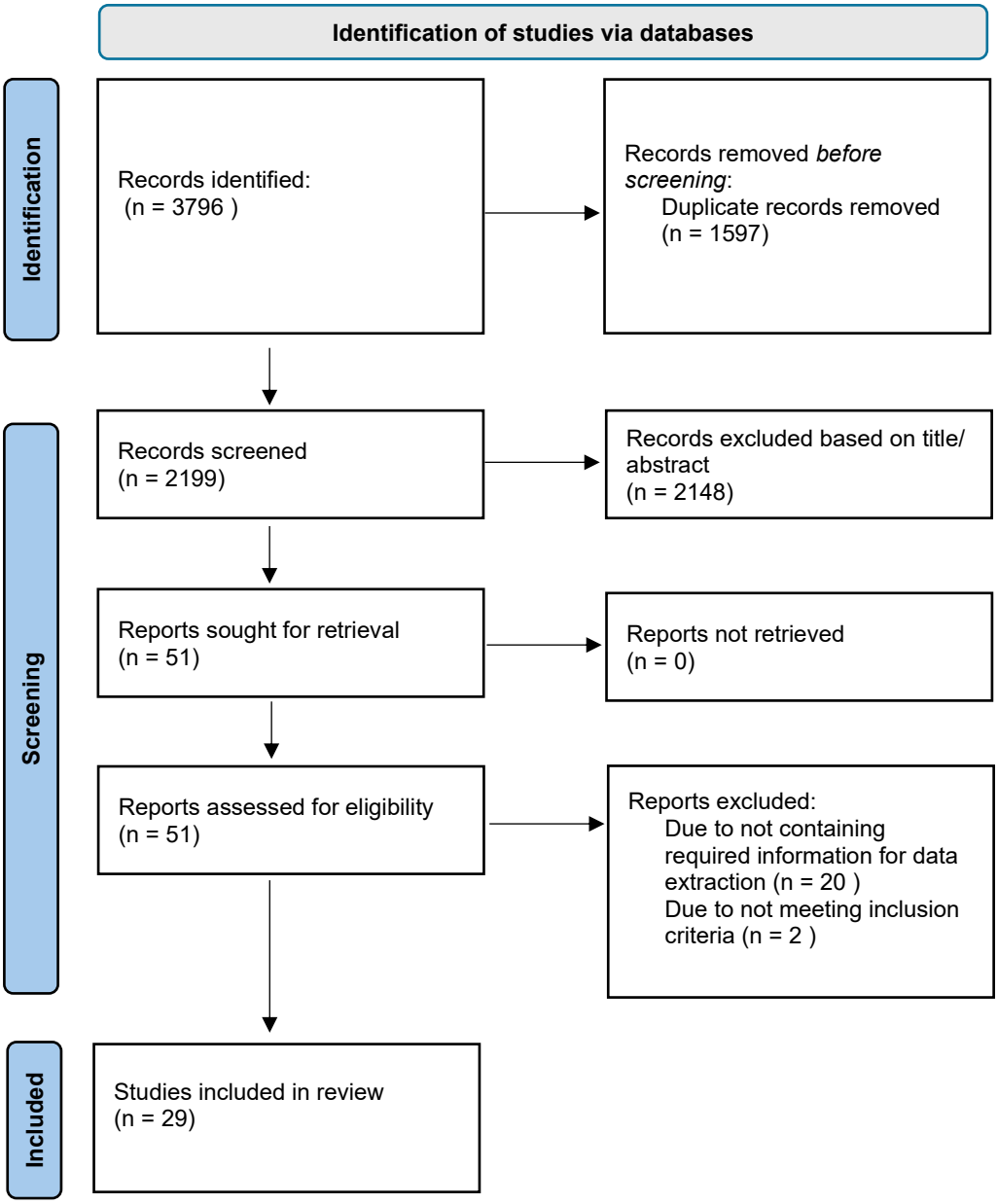
identification in some cases may instead reflect changes in the individual's awareness or knowledge of autism.

Study Selection Process

After removing duplicates, all records were screened independently by a first reviewer. At the first stage, titles and abstracts were screened against the eligibility criteria, followed by a second stage of reviewing full text if indicated. A second reviewer cross-checked a sample of 10% of the records at both stages of the study selection process to ensure agreement between screeners. All of the records were agreed upon by both reviewers.

The study selection process is depicted by the PRISMA flow diagram in Figure 1.

Figure 1: Flowchart of Study Selection



Data Extraction

Following the screening process, a total of 29 remaining studies were shortlisted for data extraction. Each study was comprehensively reviewed, and key information extracted into a table, i.e. author, year of publication, participant demographics, study design, diagnostic criteria used, intervention/ exposure details

(if applicable), outcome measures, and main findings related to loss of autism diagnosis.

Quality Appraisal

The studies were critically appraised using the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018). The MMAT is considered an efficient tool for reviewing studies with a range of methodologies (Souto et al., 2015). This appraisal was not for the purpose of excluding studies but rather to characterise the overall quality of studies included in the review. Each study was scored 0 (no criteria met) to 5 (all criteria met).

Results

Overview of Included Studies

There were 29 studies that met the inclusion criteria. Year of publication spanned 14 years; ranging from 2009 to 2023. Overall, there were a total of 14 unique participant samples included as several studies used the same participant pool from Fein et al (2013). See Appendix A for further details of which studies this applied to. Across all of the studies, there were data from N = 917 LAD participants (however, again, due to several studies using the same participant pool some participants may be included more than once). See Appendix A for full table of included studies.

Five studies included only LAD participants, with no comparison group. Two of these studies were individual case studies, whilst the other studies utilised participant samples. Whilst these studies do not inform us about similarities or differences compared to typically developing (TD) and/ or autistic (ASC) populations (i.e. the presence or absence of residual autistic traits), there are some typical

characteristics and outcomes of LAD identified. Of the remaining 24 studies, five studies compared LAD to ASC, two studies compared LAD to TD, and 17 studies compared LAD to both. There were a broad range of outcomes explored across these studies including factors related to diagnosis, interventions accessed, cognitive functioning, social functioning, behavioural functioning, psychological functioning, and co-occurring outcomes. Over half (15 studies) measured autistic traits within the LAD population, in some cases this was the primary outcome measure, whereas in other studies, such traits were identified secondary to the research question.

The majority of studies (23 out of 29 studies) utilised a cross-sectional design with data collected at one time point only. The remaining 6 studies used a longitudinal study design with data collected at 2 or more time points (however two of these were individual case studies). Consideration may be given to the study methodology for this population, given that a longer sample-based study duration with increased follow-up time points may help researchers to establish temporal sequences and causality over time and reduce cohort effects.

Quality Appraisal

As above, the Multi Methods Appraisal Tool (MMAT, Hong et al., 2018) was used post-screening to assess overall quality of studies but did not influence inclusion or exclusion. Each study was scored 0 (no criteria met) to 5 (all criteria met). Scores ranged between 2 to 5, meaning that there was variance in study quality, however most were of mid-range quality; 65% of the studies scored 3 out of 5, followed by 28% scoring 4 out of 5, 3.5% scoring 5, and 3.5% scoring 2 out of 5.

All studies had clear research questions which aimed to study the characteristics or outcomes of LAD individuals (this was a requirement for inclusion

in the review). The included studies were also deemed to use suitable sampling methods and measures. All included studies used gold-standard assessment tools, i.e. the Autism Diagnostic Observation Schedule (ADOS, Lord et al., 2012), linked with manualised diagnostic criteria (e.g. DSM-5 (American Psychiatric Association, 2013).

However, the MMAT identified several limitations with the evidence base. There is a need for larger and more varied samples. The majority of the studies also failed to meet the criteria of having representative samples due to consisting of mainly male, Caucasian, paediatric populations. Some longitudinal studies may involve a risk of non-response bias due to individuals who no longer identify with an autism diagnosis choosing not to take part in further autism-related research. It is also unclear whether confounders are always accounted for when making comparisons between groups, for example when making comparisons between groups in particular cognitive, social or psychological domains there is not always a report of participant characteristics that may influence such findings, e.g. demographics or engagement in interventions.

Characteristics and Outcomes

As there is such there is a wide and varied range of measures and outcome measures, a narrative synthesis is used to synthesise the findings below into the following categories: factors related to diagnosis, interventions accessed, co-occurring outcomes, and cognitive, social, behavioural, and psychological functioning. The subheadings were developed inductively by synthesising the studies in the evidence base. They were also loosely structured around key domains relevant to autism, such as social, communication, cognitive, and psychological

factors. This approach allowed for a narrative synthesis grounded both in the specific focus of the included studies and in established autism-related frameworks.

Factors Related to Diagnosis

Diagnostic Process. One study explored differences between children who previously held and currently held an autism diagnosis using a matched-pairs design (Blumberg et al., 2016). A strength of this study is the use of propensity score matching to reduce the influence of potential confounding variables. Participants were recruited via follow-up calls to parents who had reported their child as having received a formal autism diagnosis in a prior survey. 13% of these children were estimated to have lost the diagnosis. There was no significant difference between groups in factors related to age (age of first developmental concern, age of ASC diagnosis, or age of first engagement with support services). Children in the LAD group were significantly less likely to have had a doctor who made a referral to a specialist for diagnostic assessment than those who were currently diagnosed, instead seeing non-specialists. LAD children were also less likely to have received an ASC subtype diagnosis than those currently diagnosed.

Conflicting results were found in another study; whilst clinician judgement about the onset of developmental differences did not differ between groups, first parental concerns about development in the ASC group were reported to be on average five months later than those in the LAD group, although for both groups the average age of first parental concerns was before the child's second birthday (Orinstein et al., 2014). Those in the LAD group in this study therefore actually received specialist support earlier than the ASC group (at 26 months on average compared to 44 months).

Therefore overall, there is conflicting evidence on whether LAD individuals are likely to be seen by a specialist earlier or later than those who retain a diagnosis. However, a distinction that can be made between the studies is that the LAD group are less likely to have been *diagnosed* by a specialist (which may lend support to the false-positive hypothesis) but having a specialist *intervention* may increase the likelihood of no longer meeting the diagnostic criteria at a later stage (which lends support to the false-negative compensation hypothesis). The specialist intervention most frequently reported is Applied Behaviour Analysis (further discussion on this below).

Diagnostic Stability. A longitudinal follow-up study examined how autism features and diagnostic patterns are characterised from childhood to adulthood (Elias & Lord, 2021). Data were collected from 155 participants at 6-time points between two and 25 years of age. Of this sample, 13 (8.39%) held a diagnosis and then later no longer met the criteria for diagnosis at one of the several time points included. This varied across the sample, with over half reported to no longer meet criteria after the age of 18. 71.01% had a stable diagnostic impression (i.e. never had a diagnosis or retained diagnosis) and 28.99% had a change in diagnosis (i.e. gained or lost diagnosis). Individuals who lost a diagnosis in adulthood could be distinguished (i.e. significantly lower levels of autistic traits) from those who retained their diagnosis on ADOS Calibrated Severity Scores (CSS; adjusted for age and language ability) and Autism Diagnostic Interview-Revised (ADI-R) scores by age 5, suggesting that changes in autistic traits were gradual and begin from a young age, even if the individual ‘officially’ reaches the point of no longer meeting criteria in adulthood.

An additional longitudinal study exploring predictors of LAD identified a similar pattern: in a sample of 40 diagnosed autistic children, 15 no longer fell into the diagnostic category after two years; children who had higher initial scores of autistic traits (assessed in relation to the ADOS-2 and DSM-5) were more likely to be in the group that retain their autism diagnosis (DiRenzo, 2021). Similarly in a comparison of Childhood Autism Rating Scale (CARS) scores, those with lower scores and fewer DSM-5 repetitive behaviours at ages between 16 to 30 months were more likely to later become a part of the LAD population when assessed 42 months later (Berry, 2009).

These studies suggest that autism traits may gradually change over time for everyone, but that for those in the LAD group they pass the ‘cut-off’ threshold for diagnosis, due to scoring at a ‘lower’ prevalence to begin with. This may raise consideration about how the cut-off for diagnosis is established, and whether this change reflects a binary presence or absence of autism, or whether it is more of a spectrum and diagnostic measures are not sensitive enough to identify remaining autistic traits. This lends support to the continuum hypothesis. These studies also do not provide context as to why or how autistic traits may change over time which is explored in further detail in the discussion.

Interventions Accessed Following Diagnosis

In one study no significant differences were found between LAD and ASC groups who had received interventions, for the following intervention variables: age when intervention services were initiated, intensity of intervention (i.e., number of hours per week), and total number of hours of intervention received before 3 years of age. Early intervention was also not associated with outcome at age four in a

longitudinal study (Berry, 2009). In two studies the percentage of LAD receiving any intervention was significantly higher than those who retained their diagnosis (Kelly, Naigles & Fein, 2010; Orinstein et al.,2014). Different types of interventions were explored within the studies included in this review, namely Applied Behaviour Analysis and Neurosurgery.

Applied Behaviour Analysis. It is recognised that Applied Behaviour Analysis is a controversial approach, however the majority of studies reported this type of intervention. Further discussion of the ethics surrounding ABA is explored in the discussion section.

One longitudinal case study followed a LAD infant who received early intervention after displaying traits of autism before the age of one (Colombi et al., 2023). This individual received a parent-mediated intervention, based on the Early Start Denver Model (ESDM). The ESDM is a global intervention that addresses all developmental areas, including receptive and expressive communication, social interaction, imitation, play, cognition, motor skills, and personal independence. It is based on methods of Applied Behaviour Analysis (ABA) which reinforces target behaviours (Rogers & Dawson, 2010). In other included studies, LAD individuals appear to have received similar behavioural interventions based on ABA, (Kelley et al., 2006; Shulman et al, 2019) including in a diverse sample (Giserman-Kiss & Carter, 2019), although full details of interventions are not always reported. In a longitudinal study based in Turkey, some participants received early intensive behavioural intervention (EIBI) and the rest a comprehensive naturalistic behavioural programme, both of which were again based on ABA principles (Mukkades et al., 2014). The significant difference in percentage of LAD children who had received ABA-based behavioural interventions compared to those in a comparative ASC

group was described as “striking” in one study; as over half of the LAD group (at 56%) had received ABA before aged 3 compared to only 7% of the ASC group who had retained their diagnosis (Orinstein et al., 2014).

Neurosurgery. There was one longitudinal case study that reported on a child who underwent surgery for the removal of a benign brain tumour (Hrdlicka et al., 2019). The individual had met criteria for autism diagnosis before the surgery, and no longer met criteria following the tumour removal. Consideration may be given as to whether the traits this individual exhibited reflected being autistic or whether effects caused by the tumour closely resembled traits relevant to autism resulting in misdiagnosis (i.e. hypothesis 2: the false positive hypothesis). In this case, the tumour was located in the temporal lobe. The amygdala is associated with social judgement (difference in social judgement being a trait of autism) and may have been impacted by the tumour, resulting in a presentation similar to autism. This is difficult to determine as it is an individual case study. A larger sample of individuals who experienced similar effects may help to identify a causal link. Alternatively, assuming that the initial autism diagnosis was valid, there could be consideration of whether removal of the tumour at an age of brain plasticity allowed for compensatory mechanisms, such as learning new social skills.

In summary, it appears that overall, most LAD individuals had received some form of behavioural intervention based on principles of Applied Behaviour Analysis (ABA), with the exception of one case study. This appears to be at a higher rate than those in comparison groups. Further consideration of ABA and the link to loss of autism diagnosis is considered in the discussion section.

Cognitive Functioning

In comparisons of LAD groups with ASC and TD groups, significant differences were found in some areas of cognition but not others. These are outlined below.

IQ Scores. Several studies required a particular IQ range as part of inclusion criteria to prevent differences in IQ acting as a confounding variable. Three studies reported high IQ scores as a characteristic of the LAD group. These scores were significantly higher compared to ASC groups who had retained their diagnosis across three longitudinal studies (Berry, 2009; DiRenzo et al., 2021; Mukkades et al., 2013). However, it should be noted that those in the ASC group did not necessarily have a low IQ, but rather that those in LAD groups had a higher-than-average IQ. This is compatible with the idea that other cognitive strengths enable those in LAD groups to mask or compensate for differences (i.e. hypothesis 3, the false-negative hypothesis).

Processing Style. In one study, LAD participants did not differ from TD participants in global or local focus, whereas both groups (TD, LAD) significantly differed from the ASC group (Fitch et al., 2015) suggesting that those in the LAD group had a processing style similar to those who had neurotypical development. As this was a cross-sectional study design, it was unclear whether the LAD group's processing style changed over time to be more like the TD group or whether it had always been this way. This could be compatible with either the false-positive or false-negative hypothesis and would require longitudinal evidence to clarify.

Language and Verbal Memory. There were mixed findings related to language skills. One descriptive longitudinal study found that the LAD group had higher scores in communicative and language skills at an early age compared to an

ASC group (Mukkades et al., 2014). Six studies observed differences in pragmatic language; as well as story goodness and cohesiveness (Canfield et al., 2016), higher-level language deficits, i.e. idiosyncratic language, and self-correction dysfluency (Suh et al., 2014) and semantic language (Kelley et al., 2006). No significant differences were found across these studies in measures of receptive language, story grammar, mental state language, added/ invented details, or narrative length. One conflicting study found no significant difference between LAD and TD groups on measures of pragmatic language (Crutcher et al, 2023). No significant differences were found across studies in measures of socialisation, communication, face recognition, or most language subscales (Fein et al., 2013; Kelley, Naigles & Fein, 2010), the use of fillers (i.e. saying ‘um’ in speech) (Irvine, Eigsti & Fein, 2015), perceptual inference (Jaffe-Dax & Eigsti, 2020) or grammatical capabilities (Kelley et al., 2006). One study found that whilst LAD individuals performed similarly to TD individuals on measures of language, there may be a greater reliance on verbal memory in LAD groups due to the differences observed in strategies used to complete language and memory tasks. This results in standardised tests being unable to detect differences in language despite LAD individuals continuing to require use of compensatory strategies to perform in the same way as the TD comparison group (Tyson et al., 2013).

Two studies looked at brain activation via MRI scans. One observed activation during a language comprehension task in LAD, ASC, and TD groups (Eigsti et al., 2016). Similar activations in posterior cingulate, frontal, and temporal regions were found in both LAD and ASC groups which significantly differed from the TD group, suggesting that there was no difference in cognitive functioning between the ASC and in the LAD group. However most noteworthy, was that the LAD had

heightened “compensatory” activation than both TD and ASC groups in a range of brain regions, meaning that atypical brain networks are utilised for language abilities in LAD individuals. This may suggest that LAD individuals continue to have a different neurological profile from TD peers but are compensating in other ways. The second MRI study used the same participant pool as Eigsti et al (2016), but compared structural language impairment across TD, ASC, and LAD groups. The study concluded that structural language impairment presents similarly in ASC and LAD groups despite this group no longer meeting the clinical criteria for autism. LAD individuals continue to exhibit subtle yet consistent differences in language compared to TD groups.

In summary, there are some aspects of language and communication in which LAD groups displayed similar characteristics to TD groups, and others where they presented with residual traits more in line with ASC groups. Some studies suggest that compensatory mechanisms may be used, for example a study which suggests greater reliance on verbal memory. MRI studies that compare the different groups on language tasks have demonstrated heightened compensatory activation within the LAD group. This may suggest that LAD individuals are able to function in a way that appears similar to TD groups via compensatory mechanisms, despite continuing to have a different neurological profile.

Pitch Discrimination. One study examined differences between LAD, TD, and ASC groups in pitch perception (Eigsti & Fein, 2013). The ASC group showed the greatest ability in pitch discrimination, followed by the LAD group, and then the TD group, suggesting that the LAD group have retained pitch discrimination skills characteristic of an ASC diagnosis, but they may not be as sensitive to pitch perception anymore.

Executive Functioning. Whilst both LAD and TD groups performed within the average range on an executive functioning task, those in the LAD group performed significantly less efficiently than the TD group but more efficiently than the ASC group that retained their diagnosis. Specific aspects of executive functioning found more difficult by the LAD group compared to TD include impulsivity, set shifting, working memory, problem-solving and planning, suggesting that there may be ongoing difficulties with executive functioning in the LAD group (Troyb et al., 2013).

Academic Performance. One study examined academic abilities in LAD individuals compared to TD and ASC groups (Troyb et al., 2013). The findings suggested that all groups performed within the average range and no significant differences were found between performance of the LAD and TD groups. The ASC group scored lower on areas of mathematical problem solving and reading comprehension, though this was not seen in the LAD group.

Social Functioning

Across both longitudinal and cross-sectional studies, no significant differences were found between LAD and TD peers in social interaction or socialisation differences (Berry, 2009; Fein et al., 2013). In one study the LAD group were judged as being as likeable (engaged, friendly, warm, and approachable) as TD peers (Orinstein et al., 2015b).

However, compared to TD peers, those in the LAD group displayed less insight into social relationships and had poorer friendship descriptions (Orinstein et al., 2015b). The LAD individuals in this study also exhibited attention and self-control difficulties that may impact social abilities. One study found that although LAD individuals did

not meet the DSM-4 criteria for autism anymore, they were clinically observed to be functioning below age expectations in domains of adaptive communication and socialisation (Berry, 2009).

In one longitudinal study, compared to the ASC group that retained their diagnosis, the LAD group displayed greater understanding of intentions and emotional contagion (DiRenzo et al., 2021) supported by a cross-sectional study in which the LAD group displayed milder social difficulties in early development (Fein et al., 2013).

Based on these studies, it appears that LAD individuals display more social insight than the ASC group but less than TD peers. Perhaps they therefore do not meet the clinical threshold for diagnosis and have lower requirements for support but may still have subtle difficulties when socialising which are not recognised due to appearing engaged and likeable. This is consistent with hypothesis 3 – false negative compensation hypothesis.

Behavioural Functioning

Adaptive Behaviour and Daily Living Skills. Across three studies, no significant difference was found between the LAD group and comparative TD groups for daily living skills or adaptive behaviour (Blumberg et al., 2016; Fein et al., 2013; Kelley, Naigles & Fein, 2010). In one longitudinal study there was no significant difference found in daily living skills compared to an ASC group (Berry, 2009), whilst in another cross-sectional study LAD children were more likely to possess essential daily living skills than those with ASC (Blumberg et al., 2016).

Restricted and Repetitive Behaviours. One study found that restricted and repetitive behaviours were prevalent for the LAD group at a similar level to the ASC

group in childhood, however at the time of testing (after loss of diagnosis) were minimal or non-existent, consistent with TD comparison groups (Troyb et al., 2014). Another study found that LAD and ASC group continued to differ from a TD group on relevant social communication questionnaire scores (I.e. repetitive behaviour subscale). As there are conflicting results, it may be concluded that the presence of such behaviours may vary for different LAD individuals. Perhaps this variance is related to the initial frequency of repetitive behaviours.

Co-Occurring Outcomes

Learning Difficulties and Behavioural Outcomes. One longitudinal study identified that a number of the children who lost their autism diagnosis received an alternative diagnosis of Global Developmental Delay or Developmental Language Disorder (Berry, 2009). This was supported by a second study that found that 96% of their LAD group had their autism diagnosis replaced by another clinical diagnosis (Blumberg et al., 2016). The most common diagnosis given instead was ADHD (45.9% of sample), followed by sensory, auditory, or processing disorder (22.6%). There were also residual behavioural problems (9.2%) and learning disability diagnosis (7%). Similar outcomes have been replicated; another study found that 92% of their LAD group had received replacement diagnoses (Shulman et al., 2019), including language or learning disabilities (68%), externalising behaviour problems including ADHD, oppositional defiant disorder, or disruptive behaviour disorder (49%). One study found that those in the LAD group had greater ADHD traits than the TD group, but less ADHD traits than the ASC group (Crutcher et al., 2023). This was supported by four further studies that found ADHD status in LAD and ASC groups to be significantly greater than the TD group (Larson et al., 2022; Orinstein et al., 2015a; Orinstein et al., 2015b; Suh et al., 2016).

One hypothesis for these findings is that there is an overlap between autism and these conditions, and that as the individual no longer met autism criteria the residual traits of these co-occurring conditions may have become more apparent to be diagnosed. Another possibility is that the individual was misdiagnosed initially and as they develop it may become clearer that another diagnosis characterises their experience better.

Psychological Outcomes. One study explored comparisons between LAD, ASC, and TD groups on the Broader Autism Phenotype questionnaire dimensions and Big Five Personality Traits (Suh et al., 2016). It was found that the TD and LAD groups were most similar and did not differ from each other on most scales. However, both groups were significantly different from the ASC group.

Many studies did not measure or report on the psychological wellbeing outcomes of autistic and/ or LAD groups within their studies, despite referring to changes in functioning as “optimal” outcomes. Several studies that did explore wellbeing identified psychological difficulties in individuals who no longer meet the criteria for an autism diagnosis. Two studies found that a proportion of the LAD group were later diagnosed with anxiety (17.4% of the LAD group), depression (12.9% of the LAD group) (Blumberg et al., 2016) and/ or specific phobias (Orinstein et al., 2015b). Another study identified that 24% of the LAD group were diagnosed with internalising difficulties including mood disorder, anxiety disorder, obsessive compulsive disorder, and selective mutism, and a further 5% were given an unspecified significant psychotic mental health diagnosis (Shulman et al., 2019). However, one study did suggest that psychopathology abated over time in both LAD and ASC groups, although it decreased more in those who experienced LAD (Orinstein et al., 2015a).

To summarise, these studies suggest that the vast majority of individuals who no longer meet the criteria for an autism diagnosis will be diagnosed with a co-occurring condition including psychological difficulties. Further consideration of this is expanded upon in the discussion section.

Discussion

Summary of Findings

To summarise the findings of this review; research has been conducted across different domains of diagnostic experience, cognition, social communication, behaviour, and co-occurring behavioural and psychological outcomes. Across different areas, those in the LAD group were found to have characteristics that significantly differed from those in the TD group and were more in line with those with ASC suggesting that there may be some continuing differences from non-autistic cohorts. The areas in which the LAD group differed from their counterparts were: types of intervention received, higher than average IQ, compensatory brain activation, ADHD traits, learning or behavioural difficulty diagnoses, and mental health difficulties.

Conversely, there were also some areas where LAD individuals did not significantly differ from TD peers suggesting that they may have developed new skills or changed behaviours in a way that is more neurotypical. Those in the LAD group had an intermediate profile; they showed an ability that significantly differed from both TD and LAD groups by being ‘in the middle’ in terms of level of needs, i.e. they scored significantly higher than one group and lower than the other. Areas where this was observed include social communication, pitch discrimination, executive functioning, and on some language measures in which individuals from the LAD

group were able to perform as effectively only with greater reliance on compensatory strategies (e.g. using verbal memory). Perhaps this is characteristic of this population's experience with their autism diagnosis; they either continue to experience difficulties, but they are not significant enough to meet a threshold for diagnosis, or they appear as though they are not significantly different from TD peers but are relying on greater compensatory strategies to achieve this. These findings are compatible with both a false-negative compensation hypothesis and a continuum hypothesis.

Factors Influencing Change in Autism Diagnosis

Diagnostic Process and Differential Diagnosis

Children in the LAD group were significantly less likely to have had a doctor who made a referral to a specialist for diagnostic assessment than those who were currently diagnosed. This may provide evidence for the false-positive hypothesis, i.e. that the LAD children were initially misdiagnosed due to the diagnosing clinician not having specialist knowledge. However, the study found that they were less likely to be referred in general, which may reflect less prominent early autistic traits to prompt a referral. This may therefore also provide evidence for the continuum hypothesis which suggests that the individuals were just above the diagnostic threshold and later moved just below.

Autism is commonly seen overlapping with conditions such as global developmental delay, ADHD, and sensory processing disorder, making it challenging to differentiate between them (Hus & Segal, 2021). This was apparent in the current findings, as many of the individuals who lost their autism diagnosis reported it being replaced by another neurodivergent diagnosis. Given the similarities between these

conditions, it may be that one of these diagnoses were more appropriate than an autism diagnosis in the first place, and that this has become more apparent by the time of second diagnosis, resulting in no longer meeting the criteria, and instead being given a different diagnosis. This explanation is supported by the finding that those in the LAD group were less likely to have been diagnosed initially by a specialist – suggesting that a less specialised clinician may have had greater difficulty distinguishing between the appropriate neurodevelopmental profile. This would provide evidence for the false-positive hypothesis.

Intensive Early Behavioural Intervention

On the other hand, one of the strongest explanations arising from the findings of this review in terms of explanations for individuals 'losing' the autism diagnosis could be due to early intervention, usually in the form of behaviour therapy. In this review, a substantial number of individuals who were in the LAD groups had received Applied Behaviour Analysis (ABA). ABA is an approach used with autistic people (usually children) that draws on behavioural and learning theory to achieve goals of specific target behaviours. In the history of ABA, negative reinforcement was used in the form of punishment for undesired behaviours. Due to ethical development, in modern ABA practices there has been a shift towards a greater emphasis on positive reinforcement strategies, such as providing rewards (Kirkham, 2017). By some, ABA is considered a gold-standard evidence-based intervention, with lots of research demonstrating that individuals have improvements in scores on measurements of adaptive behaviour and functioning (Choi et al., 2022). However, it should be noted that many autistic advocates and people in the neurodiversity movement disagree with the use of ABA approaches, due to finding the fundamental ideology of the approach problematic (Kirkham, 2017). Research with individuals who have

themselves received ABA as children highlights that the experience was traumatic, and that despite them recognising some benefits, those were outweighed by significant long-term consequences (Anderson, 2022). Given that within the contemporary neuroaffirmative ecological paradigm, autism is viewed as a different neurological profile rather than a deficit, ethical issues are raised with the identification of target behaviours. These are typically based on neurotypical behaviours which are assumed to be the 'correct' behaviours that an individual must work towards, and reinforcement strategies are essentially used to encourage the individual (usually children who are arguably more impressionable and unlikely to have identified target behaviours themselves) to change their behaviour in order to act in a way that is more characteristic of a neurotypical person and agreeable for the people around them such as parents, caregivers, or educational systems. This may appear helpful given that autistic people may learn new skills that they did not possess before, and this can enable them to engage in their environment. However, changing behaviour to fit neurotypical standards is a concept commonly known as 'masking' and this is another area which has been researched widely in recent years.

Compensatory Mechanisms

In addition to the majority of the LAD group having received ABA interventions in childhood, a number of the studies highlighted compensatory strategies or mechanisms observed in individuals in the LAD group. This was seen across various domains. One study's hypothesis was that having a higher-than-average IQ allowed for "compensation of deficits" via explicit and controlled processing to substitute for weak social processing. Individuals were also observed to perform as well as their TD peers in measure of language functioning, but this required a greater reliance on verbal memory. Additional to neuropsychological test scores, this was also

evidenced biologically in studies that utilised MRI brain scans. The finding that individuals who have experienced LAD show brain activation associated with compensatory processes that is significantly different from TD peers is support for the false-negative compensation hypothesis, i.e. the recognition of autism as a lifelong neurological profile and the influence of masking and compensation behaviours.

The Impact of Masking and Compensation

Research has demonstrated that individuals with higher reported autistic traits tend to engage more in masking or camouflaging behaviour, which is in turn associated with worse mental health outcomes (Cook, Hull, Crane & Mandy, 2021). This is often driven by stigma avoidance, resulting in suppressing certain aspects of identity. Although impression management and suppression behaviours are not unique to autistic people and can be experienced by neurotypical people in some situations, research suggests that autistic people experience mask at a higher frequency and intensity; with certain experiences being specific to autistic people such as sensory suppression and masking leading to suicidal ideation (Miller, Rees and Pearson, 2021).

Research on masking has also identified a link between masking behaviours and autistic girls and women (Corscadden & Casserly (2021). Interestingly, it is commonly considered within the literature that the reason that autistic girls and women are underdiagnosed is due to an increased rate of masking behaviours, particularly in adolescence when social pressures increase and there may be heightened self-awareness of identity (Hull et al., 2020). However, some research has suggested that whilst masking may increase disparities in diagnosis for different

genders, masking should not be considered a female phenotype specific issue as this may prevent masking being considered for people of other gender identities (Pearson & Rose, 2021).

By this logic, one might conclude that masking behaviours may be prevalent amongst autistic people from all gender identities. It is possible that those who fall into the loss of autism diagnosis (LAD) groups in this review have also learned to engage in masking behaviours over time due to the increased exposure to stigma and neurotypical social norms. This would explain why they meet the criteria initially, but by the time of a second assessment, the individual has learned to function and behave in a way that will enable them to camouflage and fit in with peers to avoid stigma. It also helps to explain the findings from this review that LAD individuals continue to experience a range of negative psychological outcomes such as depression, anxiety, specific phobia, OCD, and severe psychotic disorders. This conclusion would therefore be in line with the neurodiversity perspective and recognise that the individual is not changing their neurological profile, but rather changing their behaviour in a way that is harmful to their sense of identity and wellbeing.

Meaning of Loss of Autism Diagnosis

On a literal level, losing an autism diagnosis implies that the individual does not exhibit the diagnostic criteria, and is therefore deemed not autistic. However, the outcomes of this review characterise those that have lost their autism diagnosis differently. The research that has been conducted across a broad range of outcomes suggests in reality LAD individuals have some areas of strengths, some continuing challenges, and many areas where they are able to perform similarly to neurotypical

groups but with the cost of compensatory strategies. Overall, they sit ‘in the middle’, with some remaining needs, but not ‘enough’ to meet the clinical threshold, in line with the continuum hypothesis. Whilst this group may not have the same level of need as those who have retained their autism diagnosis, there remains significant differences characteristic of autism that can be observed across a broad range of domains.

This prompts consideration of the threshold in diagnostic assessments for autism and their purpose. One criterion for this review was that all studies included a standardised measure of autism, such as the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012). This is widely considered a gold-standard measure of autism. However, limitations of its use as a diagnostic tool have been identified in the literature. One such limitation is that it only considers current behaviour and skills (when not combined with the ADI-R), meaning that the influence of camouflaging and masking behaviours may result in not meeting criteria. Additionally, a weakness of the ADOS-2 is diagnostic discrimination; social communication difficulties measured by the ASOS-2 have been found to not be specific to autism, particularly in complex clinical settings, tending to overclassify other diagnostic groups as autism (Akshoomoff, Corsello & Schmidt, 2006; Maddox et al., 2018). It is an observational assessment, based on tangible behaviours observed by an (often neurotypical) observer: eye-contact, facial expressions, gesture etc – many of which are reported by autistic people to have been the targets of masking behaviour. Therefore, it highlights the importance of a multi-informant, multi-modal autism assessment.

The findings of this review that identify the LAD population as having differences that may fall just below the diagnostic threshold give cause to think about

whether the diagnostic assessment is truly able to make a binary diagnosis (i.e. the individual either does or does not have autism if they do not meet this specific threshold). These individuals display outcomes that are significantly different from neurotypical groups across multiple domains. Given that autism is widely considered a spectrum, perhaps these individuals are still autistic (in line with a neurodiversity approach which would assume this is their lifelong neurological profile) but their position on the spectrum has shifted through the use of compensatory and masking mechanisms. The idea that an individual's presentation of autism may naturally shift across the spectrum over time is supported by a diagnostic stability study in this review that found that autistic traits changed over time across all participants, including LAD, neurotypical and autistic people (Elias & Lord, 2021).

Another consideration may be the reliance on diagnostic tools such as the ADOS-2 to provide definitive "answer" on diagnosis, as opposed to using such tools as part of a multi-faced assessment as intended (Bishop & Lord, 2023). This approach to autism assessment has been criticised as it does not align with the neurodiversity perspective (Timimi et al., 2019). Perhaps with this in mind, this diagnostic tool actually indicates a measure of the level of tangible, non-autistic behaviours in social communication domains (which can be learned), rather than truly indicating the person's neurological profile (consisting of a different way of processing social and sensory information). For example, in this review LAD and ASC groups were shown to have greater pitch discrimination abilities than those in the TD group. This prompts a critical reflection of how meaningful the historical deficit-focused model is. Alternatives to this model of diagnosing autism as a pathology include utilising a social or ecological model which, in line with the neurodiversity paradigm, would focus less on what an individual cannot do and

consider these ‘deficits’ in the context of attempts to fit into an environment with differing neurotypical norms (Anderson-Chavarria, 2021; Mandy, 2023).

Limitations

This review encompasses a wide range of studies, representing various study designs and outcomes. The predominance of male, white populations underscore the need for greater diversity and representation in research on LAD. This is particularly relevant as the outcomes of this review highlight the importance of masking and camouflaging behaviours. As mentioned above, this is known to be more prevalent in autistic female populations. However, given that autistic girls and women are underrepresented in the literature, this may not be fully explored.

There is also an over-representation of paediatric samples, meaning that a majority of the evidence looks at children and how they have ‘lost’ the diagnosis in childhood or adolescence. It would be helpful and extremely relevant to the explore the ‘loss’ of autism diagnosis in longitudinal studies that follow participants as they age into adulthood and older adulthood. Children and adolescents may be susceptible to engaging in increased masking and compensatory behaviours due to increased self-awareness of identity during this stage of development (Erikson, 1994).

The studies included in this review are predominantly cross-sectional, which is a notable limitation of the existing literature. Longitudinal studies, in contrast, allow for the observation of transitions in autistic traits, diagnostic stability, and masking behaviors over time and across developmental stages. This approach would be especially useful in areas where outcomes remain unclear. For example, LAD individuals were found to have similar processing styles to the typically developing

group, but it was unclear whether this had always been the case or developed over time. Longitudinal studies could help clarify such developmental trajectories.

It should be noted that the majority of studies had small sample sizes, which may mean that they lack sufficient statistical power to find effects between groups. This may mean that some studies report there being no significant differences between groups where there is one. However, given that there was a mixture of study sizes that consistently found significant differences for the LAD group against both TD and ASC groups, this would strengthen the suggestion that LAD are a unique group that have needs and abilities that fall 'intermediately' between those in comparative groups.

Lastly, there are inbuilt assumptions informing the literature which have influenced what is and is not measured. Within the deficit-model paradigm of autism, diagnostic measures can be seen to reflect the presence/ absence of traits which are seen as the problem to be treated. Therefore, outcome measures include functional outcomes based on individual-level factors (e.g. cognitive domains like IQ and language). 'Optimal' outcomes are assumed to be those in which the level of autistic traits reduce. On the other hand, if one were to view autism through an ecological model paradigm, autistic traits are not inherently viewed as the problem. There is greater curiosity of the person's own life goals, wellbeing, and interaction with the environment, including the use of masking and compensation behaviours. Rather than aiming for a reduction in autistic traits, optimal outcomes would be defined as greater wellbeing and mental health.

Conclusion

To conclude, the findings of this review provide compelling evidence for a number of alternative hypotheses to the historical deficit-recovery model of autism diagnosis. It is likely that the LAD occurrence is due to a combination of the aforementioned hypotheses, rather than one sole explanation. The findings of this review provide the strongest evidence for the false-negative hypothesis in combination with the continuum hypothesis, although there is some evidence that for some individuals LAD could be explained by the false-positive hypothesis, particularly in the context of differential diagnosis and the overlap between neurodivergent conditions.

Implications and Directions for Future Research

This systematic review highlighted that a broad range of outcomes have been researched in individuals who have lost an autism diagnosis. Interestingly, a greater number of research studies have focused on cognitive and behavioural abilities, particularly aspects of language. Fewer studies have examined psychological wellbeing, and none of the included studies reported the views of LAD participants, which is worth considering given that the individuals are considered to have reached "optimal" outcomes, and it is unclear from the included studies whether the participants would also consider themselves to have reached "optimal" outcomes. This review did not include qualitative studies, which may be more likely to explore autistic adults' views on what is considered an optimal outcome in more detail. Future research would also benefit from focusing on the lived experience of autistic people and how they experience no longer meeting the criteria for an autism diagnosis.

There are a number of suggested implications when considering support for autistic people. Firstly, there is a consideration of the diagnostic process. The findings of this review suggest that there is a benefit of early, accurate diagnosis, in line with NICE guidelines (NICE, 2021). Early diagnosis may occur prior to individuals developing camouflaging and masking behaviours that may develop over time in response to societal stigma and pressure to conform. Accuracy of diagnosis is also important given there were a large number of individuals whose diagnosis was later replaced by another neurodevelopmental diagnosis that was deemed to be more suitable. This will ensure that individual and their network have the most appropriate understanding of their neurological profile.

There may also need to be consideration of the diagnostic process and post-diagnostic support. Clinicians may benefit from taking a person-centred, ecological approach to autism and autistic traits, i.e. considering personal accounts of an individual's dynamic interaction with the environment rather than viewing autistic traits as a fixed measurable deficit to be overcome. This may include assessing a balanced profile of strengths and difficulties, including masking or camouflaging strategies that may have developed over time. A nuanced consideration of developmental history, current circumstances, and the individual's views alongside clinical judgement may help to observe changes in behaviours that may indicate camouflaging rather than the absence of autism.

Following diagnosis, consideration may also be given to the support that is offered to autistic individuals. ABA was one of the most common interventions given to the LAD individuals within the included studies of this review. Whilst these individuals no longer meet the diagnostic criteria for autism, there is evidence that autistic people have had negative and even traumatic experiences of ABA which has

been linked to masking. Both masking and ABA have been linked to negative long-term psychological outcomes. This leads back to the question of what is considered ‘optimal’ outcomes. Given the paradigm shift of autism as a neurodiversity rather than a deficit, perhaps the idea of ‘losing’ the autism diagnosis as an ‘optimal’ outcome is outdated, and instead, the optimal outcome should be identified in collaboration with autistic people themselves, who may actually prefer and benefit psychologically from neuro-affirmative approaches developed through co-production (Chellappa, 2023; Cullingham et al., 2023).

To conclude, a suggestion for future studies and practice therefore is to research and re-define the meaning of optimal outcomes for autistic people. It would be useful to gain increased insight into autistic individuals experiences via both qualitative and quantitative studies in order to consider the interaction between a person and their environment. Future studies should critically appraise the existing diagnostic tools and consider a greater range of masking and compensatory behaviours that contribute to the meeting or not of diagnostic criteria.

One clinical implication is that the prevalence of masking and compensatory behaviours may shed some light on how and why autistic people are underdiagnosed. Given the psychological impact identified for this LAD group, it is important in clinical practice to prioritise autistic wellbeing over the ability to present as neurotypical, which may mean revisiting current diagnostic and therapeutic practices and updating them or finding alternative methods. Those who have ‘lost’ their autism diagnosis may require further support to explore whether there is a more appropriate neurodivergent diagnosis, or whether they may be engaging in masking/ camouflaging behaviours which can be detrimental to self-esteem and sense of identity. It would be helpful to research alternative evidence-based support, such as

neuro-affirmative behavioural approaches, which could be developed via co-production to ensure that the support is meaningful to autistic communities.

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Part 2: Empirical Paper

Improvement in anxiety, depression, and/ or related emotional difficulties in autistic adults

Abstract

Aims: Research suggests that mental health provision does not adequately meet the needs of many autistic adults. This study aims to understand the individual meaning and lived experiences of self-reported mental health improvement in autistic adults.

Method: Semi-structured interviews were conducted with a community-based sample of 15 autistic adults. Interviews were transcribed and coded using reflexive thematic analysis. Two autistic experts by both lived and research experience were consulted at the design and interpretation stages of this study.

Results: There were four overarching themes and several sub-themes interpreted from the data. These include 1) personal, 2) interpersonal, 3) environmental, and 4) strategies/ support. Personal subthemes include ‘cognitive factors’, ‘emotional factors’, and ‘intersection with identity’. Interpersonal subthemes include ‘social selectivity’, ‘value of friendships’, ‘connecting with other autistic people’, ‘pressure to conform as harmful’, ‘social mismatch and misunderstandings’, and ‘vulnerability to mistreatment’. Environmental subthemes include ‘societal lack of understanding’ ‘barriers to support’, ‘mental health stigma’, ‘housing’, ‘sensory environment’, ‘accommodations’, and ‘access to resources. Subthemes of strategies/ support were ‘self-management strategies’, ‘experiences of therapy’ and ‘support beyond therapy’.

Conclusions: Themes highlight the need for neuro-affirmative approaches to autistic mental health on individual, interpersonal and environmental levels, i.e. considering the person-environment fit in a social model of autism. Therapeutic support should focus on validation and self-esteem to reduce the pressure to mask. Environmental support involves providing accommodations and increased understanding of autism.

Introduction

Autistic Mental Health

Anxiety and depression are among the most common mental health conditions in the general population (Vos et al., 2016). Research has identified that autistic people in particular are at a greater risk of common mental health difficulties, negatively impacting quality of life (Hollocks et al., 2018; Lai et al., 2019). Despite this, there is a limited amount of research exploring the lived experiences of autistic adults with mental health difficulties. There is growing evidence that autistic mental health also includes other experiences which are relevant to but distinct from anxiety and depression, such as burnout, social camouflaging, masking, and meltdowns (Higgins, Arnold, Weise et al., 2010; Raymaker et al., 2020; Hull et al., 2021). All of these may contribute towards overall psychological distress but would be unlikely to be captured in the existing standardised mental health measures. The current study aims to bridge the gap of knowledge about the broader experience of emotional difficulties within the autistic population, encompassing all of the above experiences.

This lack of understanding also translates into clinical practice, where research has identified that further training and adaptations to intervention protocols are required to allow therapists to support autistic service-users more competently (Cooper, Loades, & Russell, 2018). Autistic people and stakeholders have identified adapted mental health interventions as a key priority (Cusack & Sterry, 2019; Roche et al., 2020). Adapted treatments and tackling health inequalities for autistic people are also an NHS priority (NHS Long Term Plan, 2019).

Current Mental Health Provision for Autistic People

NICE guidelines outline a number of approaches for supporting autistic people that should be driven by the individual and their families' preferences (NICE, 2021), however, in practice, research has highlighted that many autistic people perceive a number of shortfalls with the current mental health support available to them; therapists having a lack of knowledge of autism and/ or inability on the part of the therapist to tailor intervention in a way that meets autistic needs (Adams & Young, 2020), receiving inappropriate interventions that target changing core autistic traits as opposed to interventions focused on mood (Cleary et al., 2022), or even being turned away from mental health services when disclosing that one is autistic (Maddox et al., 2019). A systematic review of current provision concluded that currently, services do not adequately support autistic adults, and can even cause additional harm (Brede et al., 2022). The lack of adequate support may even be amplified when considering intersectionality with other aspects of marginalised identity, such as mental health difficulties in transgender autistic people (Strauss et al., 2021). There is therefore compelling evidence that the current provision is not meeting the needs of autistic people with mental health difficulties. There is some literature on adaptations that can be made to mental health support (Loizou et al., 2023; Riches et al., 2023), however exactly how adaptions should be made remains unclear and further research is required. On the other hand, it may be the case that it would be more useful for autistic people to improve their mental health in different formats entirely.

Mental Health Improvement and/ Or Recovery

To understand more about how to improve mental health support for autistic people, this study aims to explore experiences of mental health improvement and/ or recovery. It should be clear that recovery from depression, anxiety or related

emotional difficulties in this study is distinct from any ideas of ‘recovery from autism or autistic traits’ (as may be referred to in some frameworks such as Applied Behaviour Analysis) but refers to recovery from common mental health difficulties. Exploring individualised meanings of recovery is particularly pertinent because research has identified a range of different conceptualisations of mental health recovery across different populations. For example, individuals deemed at-risk of suicide defined recovery as ‘the ability to manage one’s own life’ (Sellin, Asp, Wallsten & Gustin, 2016), whilst a sample of substance-users emphasised aspects like ‘feeling useful and accepted by others’, ‘self-love’, and ‘identity’ (Brekke, Lien, Davidson & Biong, 2017). Some research has emphasised social factors related to recovery (Tew et al., 2011), whilst limited research in autistic samples suggests a focus on the person-environment fit (Henninger & Taylor, 2012). Differences in ideas about recovery have been observed between clinical staff and service users, concluding that recovery is ultimately a difficult-to-define and idiosyncratic concept (Aston & Coffey, 2011).

In light of this, the present study will allow participants to self-define their own experience of recovery or improvement. This has been done successfully in previous research, e.g., with individuals with borderline personality disorder (Ng, Townsend, Miller, Jewell & Grenyer, 2019). This allows the present study to gain a greater insight into how mental health recovery is experienced and conceptualised within the autistic population. This could help to inform more effective ways of measuring mental health outcomes in clinical services and future research.

Community-Based Research

A systematic review on anxiety and depression in autism found the literature to have a high degree of heterogeneity, linked to an overreliance on clinical samples (Hollocks et al., 2018). The present study aims to understand more about the lived experience of autistic adults via a community-based sample. This is pertinent as there are often barriers to seeking a diagnosis within autism services and therefore many individuals choose to self-identify, meaning not everyone would be known to the autism services that clinical samples would be likely to recruit from (Malik-Soni et al., 2022). It also allows the study to include a greater pool of participants who may have developed alternative ways of coping other than engaging in clinical mental health interventions and could therefore capture a more naturalistic experience of improvement in mental health that may not have been captured in the existing evidence base. In fact, the above-mentioned study in a BPD sample found that qualitative lived-experience research emphasised different personal aspects of recovery entirely to those typically measured clinically, highlighting individual motivation, hope, and activities (Ng, Townsend, Miller, Jewell & Grenyer, 2019). It is possible that research within an autistic community sample may also differ from clinical outcomes, which could be valuable insight for the adaptation and/ or reform of current mental health provision.

Study Aims

In summary, the present study aims to build on the existing research and address gaps in knowledge by 1) exploring autistic lived experiences of depression, anxiety and related emotional difficulties, 2) understanding how mental health recovery and/ or improvement may be defined within this population, and 3) understanding how mental health improvement has been experienced in a community sample. It is anticipated that the findings will increase understanding of

the important aspects of mental health recovery to influence and improve best practice for autistic mental health support.

Method

This study is reported against the Standards for Reporting Qualitative Research (SPQR) guidelines; a 21-item checklist for qualitative research (O'Brien et al., 2014).

Research Design

This study utilised a qualitative research design using semi-structured interviews to explore autistic adults' experiences of self-identified improvements in anxiety, depression, or related emotional difficulties. The research approach was Reflexive Thematic Analysis (RTA) as developed by Braun and Clarke (2021). There were several justifications for using this approach. Firstly, RTA is not bound to any particular theoretical framework, allowing the research to be shaped by the data itself rather than preconceived theories. This flexibility is valuable for a study that aims to capture the unique and idiosyncratic experiences of autistic adults. Secondly, RTA allows for a detailed and nuanced understanding of participant experiences. Given that mental health recovery is a highly individualised and complex experience, the approach allows for themes to be explored in depth. Thirdly, an integral part of RTA is researcher reflexivity, where researchers reflect on their own biases and assumptions pertaining to the research. Particularly in the context of analysis being interpreted by a non-autistic researcher, reflexivity is a useful aid to recognise the unintentional influence of any neurotypical assumptions on the research process and to promote authentic representation of participant experiences.

Epistemology and Ontology

An inductive approach was employed to explore the experiences of mental health improvement and/ or recovery among autistic adults. This means that rather than starting with a predetermined hypothesis, the data was collected from participants through semi-structured interviews, and themes and patterns were identified via detailed analysis of their narratives. The analysis adopted a critical realist approach. Critical realism allows the study to recognise that there is an objective reality in which mental health improvement takes place, but that the lived experience and meaning of that recovery may be subjective, involving both socially and individually constructed meaning that participants attach to their experiences.

Overarching themes of personal factors, interpersonal factors, environmental factors, and strategies were interpreted from the data analysis, whilst ensuring the findings were grounded in the participants' narratives. Although these categories align with existing ecological theories of autism such as the person-environment fit (Caplan, 1987; Henninger & Taylor, 2012; van Vianen, 2018), they were not pre-determined, in line with an inductive approach. This approach ensured that the research remains firmly rooted in the actual experiences of autistic adults, reflecting both the objective and subjective dimensions of their mental health experiences.

Researcher Positionality

The primary researcher's positionality is influenced by multiple intersecting factors that may have shaped perspectives, biases, and approaches to the study. The primary researcher, a late twenties, female, UK-based Trainee Clinical Psychologist of mixed ethnicity, identifies as neurodivergent, with diagnoses of ADHD and dyspraxia. As such, the researcher aligns with neuroaffirmative approaches that consider intersectionality. Researcher identity may have impacted

some research decisions, such as the use of purposive sampling to ensure a diverse sample, prioritising participant comfort during interviews and sensitivity to language used in data analysis. Whilst this identity offers both lived and clinical insight into neurodiversity in relation to mental health, it is important to note that the primary researcher does not identify as autistic. Consultation meetings with autistic adults, alongside ongoing reflexivity, were employed to minimise the potential impact of researcher influence and bias. This included seeking feedback on interview protocols and data interpretation. It should also be noted that Clinical Psychology doctoral training in the UK is rooted in both neurotypical and Westernised paradigms of mental health and interventions, which may influence how the data was conceptualised and interpreted. Efforts were made to critically reflect on and challenge these paradigms throughout the research process.

By addressing researcher positionality, the aim is to enhance the transparency of the study findings and interpretations, whilst also recognising the importance of platforming the voices and experiences of autistic adults in the research process.

Consultation Group

Two autistic individuals with experience in qualitative research formed a consultation group with the researcher and were consulted for two 1.5-hour group meetings at both the design and analysis stages of the research. Consultation meetings were held remotely via video call and made use of the shared screen function to enable the group to review and feedback on relevant study materials and ideas. Feedback given by the group was a valuable aspect of the research process, particularly in reflecting on neurotypical biases such as considering how particular

language may be perceived, and conceptualising themes in ways that authentically capture the autistic experience expressed by the participants. In line with an ethical approach to autism research, the members were compensated for their contributions.

Ethical Approval

A research protocol, data protection, and ethics application were reviewed and approved by academic staff and the University College London Research Ethics Committee within the Doctorate in Clinical Psychology at University College London (Project ID: 24669/001). Due to the potential for distress when discussing highly personal and sensitive topics, the research study was treated as a high-risk application. Careful consideration was taken to minimise/ prevent risk of emotional harm to participants, such as providing an interview schedule in advance to reduce uncertainty, offering a choice of interview formats, offering accommodations throughout the research process, offering check-ins and breaks, and monitoring for verbal or non-verbal signs of distress during the interview. All participants were provided a debrief sheet containing sources of support in case they had found the interview experience challenging.

Study Materials

Materials relating to the study included a digital recruitment poster, online screening survey, information sheet with an attached semi-structured interview schedule, a consent form, and a debrief sheet (see Appendices). Interview questions were developed by drawing from similar qualitative research exploring mental health recovery in other populations (e.g. Ng, Townsend, Miller, Jewell & Grenyer, 2019) and discussion with supervisors initially. All materials were then discussed and/ or

reviewed by the UCL Ethics Committee and autistic consultation group. Further adaptations were made where necessary.

Recruitment

Recruitment & Sampling Strategy

The study recruitment poster was disseminated digitally to various autism support groups across the United Kingdon, University College London student support service, and within the Autistica Insight network (an online platform for autistic people to take part in research). Participants expressed interest in taking part in the study by responding directly to the advert by email. Following this, participants were sent the information sheet and a brief consent form for the screening survey. If, after considering the information, the participants decided that they would still like to take part, they were invited to complete a screening questionnaire which collected demographics (age, gender, and ethnicity), RAADS-14 scores (Eriksson, Andersen, & Bejerot, 2013) and DAAS-21 scores.

There were 245 responses at this stage. It was predetermined that there would be a maximum of 15 participants selected for interview. In recognition that in reflexive thematic analysis, meaning is generated through the interpretation of data rather than excavated, objectively identifying an appropriate number for data saturation was not believed to be consistent with the assumptions of the reflexive thematic analysis approach (Braun & Clarke, 2019). Therefore, the decision for 15 participants was made in balancing funding resource with a large enough sample to generate a diverse range of views and experiences. Purposive sampling was used to select participants within a broad framework that would incorporate a range of

ages, genders, and ethnicities. Where there were multiple participants who could be selected and maintain the desired demographic quotas, random selection was used.

Participant Demographics

A total of 15 participants were recruited from community-based settings, ensuring a diverse sample that included voices underrepresented in autism research. Regarding gender, the sample was 40% male, 40% female, and 20% non-binary. The ethnicity of the sample was 13.3% Black, 20% Asian, 53.3.% Caucasian, and 13.3% of Mixed Ethnicity. The sample was divided into five age brackets of 18-24, 25-34, 35-44, 45-54, and 55-64, with each age bracket representing 20% of the total sample, contributing to a distribution across age groups. All participants scored above cut-off on the RAADS-14 questionnaire (Eriksson, Andersen, & Bejerot, 2013).

Inclusion criteria:

1. Adults (18+) who identify as autistic, whether self-identified or formally diagnosed. Including self-identified autistic individuals was intentional due to the well-documented underdiagnosis of autism, particularly among marginalised groups. This approach acknowledges the health inequalities that contribute to missed or delayed diagnoses, allowing for the inclusion of diverse experiences that might otherwise be excluded (Lewis, 2017).
2. Experience with anxiety, depression, and/ or related emotional difficulties (i.e. burnout, masking, social camouflaging, and meltdowns). These experiences are closely related to depression and anxiety and are pertinent to autistic people but are not yet captured in diagnostic criteria (Higgins, Arnold, Weise et al., 2010; Raymaker et al., 2020; Hull et al., 2021).

3. Willingness to participate in a semi-structured interview in one of the following formats: face to face, video call, telephone, or chat-based interview.

Exclusion criteria:

1. Participants who would be deemed at a high risk of psychological harm if they were to take part in an interview, as indicated by DASS-21 questionnaire scores (Lovibond, 1995). For example, participants who are currently experiencing an extremely elevated level of distress and may need direct intervention. This decision was made to reduce risk of harm to participants.
2. Participants with a diagnosed learning disability. Whilst it is recognised that there is high co-occurrence of autism and learning disabilities, this decision was made to ensure that the findings were pertaining to the unique autistic experience of mental health improvement rather than challenges relating to living with a learning disability. It also meant that all participants had the ability to partake in semi-structured interviews.
3. Scoring below the cut-off on the RAADS-14 questionnaire, a measure of autistic symptoms (Eriksson, Andersen, & Bejerot, 2013).

Interviews Procedure

Participants who were selected to take part were contacted via their indicated preferred communication method and invited to take part in an interview at a time and format that suited them. 13 out of 15 participants opted for online interviews via Microsoft Teams, 1 participant opted for a telephone interview, and 1 participant opted for a face-to-face interview. All participants were given practical instructions such as how to access Microsoft Teams (virtual) or the interview location (for the face-to-face interview), a reminder of the interview schedule and an opportunity to

discuss any queries. Participants then signed a second consent form outlining the interview process and their right to withdraw from the interview at any point. Participant information was pseudonymised. A document that links pseudonyms and participant information was stored securely in a separate location to protect confidentiality, in line with data protection protocols.

During the interview, the researcher asked questions following the interview schedule, which outlined an overview of topics with potential follow-up prompts (see Appendix). The researcher aimed to increase participant comfort during interviews and therefore interviews were conducted in a conversational style with multiple opportunities for check-ins or breaks. Each interview lasted on average 75 minutes. At the end of the interview, participants were offered a debrief. None of the participants expressed feeling distressed by partaking in the interview. All participants were given the option of receiving a voucher or cash to thank them for their contribution to the study. They were also sent the debriefing document containing sources of support at this stage.

Reflective notes were made throughout the research process to keep track of key research decisions, to aid reflexivity in line with the Reflexive Thematic Analysis (Braun & Clarke, 2021) approach, and to consider for the critical appraisal.

Transcription and Analysis

Some interviews were transcribed automatically via Microsoft Teams software. However, the researcher listened to recordings of all interviews to ensure accuracy of transcripts. As the study utilised a critical realist approach, focus was given to the semantic content, with occurrences such as pauses, stutters, inarticulacy, or repetition omitted. This also helped with data familiarisation, the first stage of

Reflexive Thematic Analysis (Braun & Clarke, 2021). The full six stages and how they were applied to the data are outlined in Table 1 below. Although they are considered sequential, they are also iterative, with movement back and forth between various stages. See Appendix H for example procedure of analysis.

Table 1 Six Stages of Reflective Thematic Analysis as Developed by Braun & Clarke (2021)

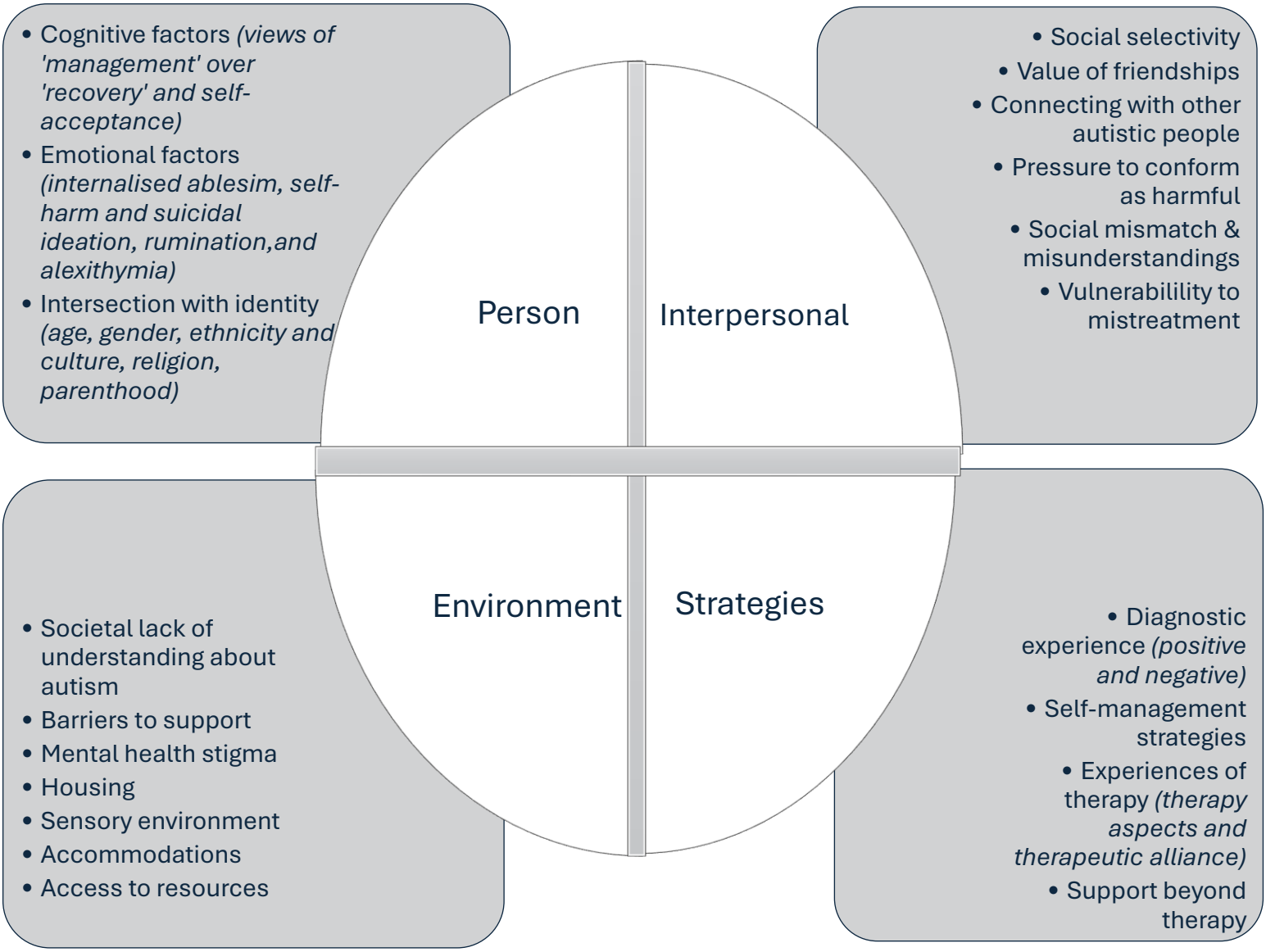
1.	**Data Familiarisation:** All interview recordings were re-listened to and used to ensure accuracy of written interview transcripts. After which, recordings were deleted.
2.	**Coding:** Using NVivo software, interview transcripts were coded according to the content of responses. After several interviews, patterns in codes began to emerge and themes were merged into codes. This process continued as more transcripts were coded and themes became clearer.
3.	**Generating Initial Themes:** Codes were reviewed to find patterns of meaning that formed broader themes. They underwent a continuous refining process.
4.	**Reviewing Themes:** Themes were continuously reviewed, including collapsing, or expanding, as necessary. It became clear that the themes could be categorised into personal, interpersonal, and environmental themes at this stage. There remained a 4th theme which linked to all of the above but was central to the research question, “strategies/ support”. It was believed this encompassed a new category. Several themes and sub-themes were identified. Themes were shared and discussed with a research supervisor and the autistic consultation group.

5. **Defining & Naming Themes:** At this stage, particular consideration was given to the neurotypical language used to define themes with the support of the autistic consultants. For example, “interventions” was renamed “strategies” in recognition that it was a combination of things that both the autistic individual did as well as support they received. “Social difficulties” was renamed “social mismatch” to prevent locating the social difficulties within the individual and instead objectively report what the participants were sharing, which was misunderstanding between both autistic and non-autistic people.
6. **Write-up:** This involved reporting themes and interpretations with relevant data extracts, with careful consideration to convey the original nuanced meaning of the autistic adults and relating this to the research question and wider evidence base.

Results

Four overarching themes identified include 1) personal factors, 2) interpersonal factors, 3) environmental factors, and 4) strategies/ support. Within each of these broader themes, there were several sub-themes. Figure 1 below shows a summarised overview of themes. Further explanation of each theme is detailed below.

Figure 1 Summary of themes and sub-themes



1. Personal Factors

There were a range of personal factors discussed by participants when considering their mental health improvements. This theme encompasses subthemes 'cognitive factors', 'emotional factors', 'intersection with identity', and recognition that 'every autistic person is unique'.

1.1 Cognitive Factors

This theme relates to individual cognition-level factors relating to autistic adults' mental health. Participants spoke about the positive influence of personal knowledge, beliefs, attitudes, understanding, and perceptions.

Views of 'Management' Over 'Recovery'. Several participants discussed how it has been helpful to them to think about their mental health in terms of 'management' rather than recovery, in recognition that it would likely be an ongoing consideration in their lives:

> P11: "I suspect we'll always have problems and it's how to deal with it better."

They considered this way of thinking about their mental health important. Adding to the idea of emotional difficulties remaining over time, some spoke about the nature of them occurring in "relapses", where the difficulties may become worse at times and better at others:

> P15: "I think the word "recovery" is interesting because I think, umm, I think people seem to think of it like you're ill then you're better. It's not sort of like a linear thing. I think it's important for people to realise that there's also going to be relapses in a lot of cases and that it's going to go up and down."

Having the tools to regulate their emotions in these instances appeared to be a goal for many participants:

> P13: "I think everyone could always handle an emotion differently in a way that it could be more effective for them."

There was indication that the absence of difficulties was not the goal, but rather the ability to manage the problems as they arise:

P12: “But I think it's just accepting that this is how it is for me, and as long as I can manage it then it's not going to ruin my day or my life or whatever.”

The importance of this inclination to recognise small improvements rather than aiming for absence of emotional difficulties was echoed by other participants:

P7: “Even if it's a very small bit of improvement or like gaining one new tool that works in one situation it’s like maybe in the grand scheme of things a very small improvement, but it’s important and kind of stacks up.”

One participant related the ongoing nature of emotional difficulties to being autistic:

P14: “I think you can't avoid the struggles when you're autistic, no matter how well you have self-managed.”

However, one participant did speak of the management of their mental health in relation a marked improvement and aiming to avoiding their mental health deteriorating to how it was previously, which may be more in line with a recovery model:

P4: “I guess the main thing is, it's just trying to avoid falling back into that pit again.”

Self-acceptance. Many participants discussed the importance of self-acceptance as part of the process of overcoming or reducing their emotional difficulties:

P12: “It's kind of self-compassion, I suppose it's the biggest thing, you know, I think the problem with autism is they've always sort of wanted it to be fixed, you know? So, you can be the same as everybody else. But I think it's nice to kind of be able to go actually, maybe that's not going to be possible. And it

kind of takes the pressure off so that you can be a bit more compassionate, and you can sort of say no… that doesn't make me a bad person. This is self-care."

Participants spoke about how they reached a place of self-acceptance by gaining a greater self-awareness of their needs:

P6: "Now I understand myself better, so I know what's gonna work for me and what's not gonna work for me."

As well as having a greater understanding of autism:

P12: ""So, I think it was like that, like light bulb moment, you know, kind of going "Ohh. My God, that is so simple. That makes sense now. I'm not weird!""

This participant spoke of how they had reached a place of self-acceptance by holding a positive perception of difference in neurodiversity:

P12: "It'd be nice for left-handed people not to have to be pressurised into being right-handed, you know, that's how I look at autism is that it's not a disease, it's not an illness, it's a condition and it's no different to somebody being left-handed instead of right-handed, except the bulk of the people in the world are right-handed."

This self-acceptance extended to resisting the pressure to conform to neurotypical standards:

P15: "So, I think a change of mindset in that sense, it's sort of the realisation that at the end of the day it's never gonna be that you look up "normal" or "average" or anything like that in the dictionary and see me, because you

won't. But actually, then it's also the realisation that actually I don't care. And that's actually OK that I don't have to sort of be “normal” like that. I mean, what is normal? It’s just what people or what society says you should be.”

Self-acceptance was described as helpful in contrast to the way one is treated by others:

P3: “So being taught to be self-accepting towards myself and recognising that the outside world definitely isn't gonna treat me that way is actually good enough.”

1.2 Emotional Factors

This theme encompasses the emotion-based factors related to autistic adults’ mental health and their journey towards improvement. These sub-themes overall relate to threats to wellbeing rather than factors that they found helpful.

Emotional Impact of Internalised Ableism. Several participants spoke of the emotional trauma they experienced by being autistic in a neurotypical society, and how this manifested in internalised emotions such as shame, self-criticism, and isolation:

P5: “I mean because it's traumatic enough actually just being in a neurotypical world that's not designed for neurodiverse people, but especially if you've never had any acknowledgement that that is the reason that, you know, you don't have the same sort of success or progress pathways as neurotypical and if you just think oh, it's because I'm lazy, I'm stupid.”

P4: “And then there's trying to kind of.. kind of.. somehow fit into the - in the sort of lanes of other [neurotypical] people in where they do or say things with

such ease and like deal with all this and that and it just mounted and mounted and mounted."

The experience of trauma was also linked to developing depression:

> P14: "And I'm thinking right, OK, I have to be like that. I've gotta be those things and I've gotta be these other things. And very much trying to model myself off neurotypical family members, and... nothing. I think that's turned out to be a nightmare because none of it seemed to work. I would always get so far, and I would think right, there's something wrong with me. I'm getting depressed."

One participant highlighted the significance of this trauma and how this had developed over many years, whilst also recognising that it was so deeply embedded in their life that this had become a part of who they are.

> P2: "A few traumatic injuries would have been much easier than the psychological trauma of years and years of this. But it's made me who I am."

Self-Harm and Suicidal Ideation. Some participants spoke about how thoughts of suicide and engaging in self-harm became a way of coping with the emotional difficulties that they were experiencing:

> P12: "I'd start shouting and crying and screaming. And because that was unacceptable, it was almost like it had to go somewhere. And because I could no longer scream or shout or whatever, and I was controlling this sort of thing, it was almost like if I could have a physical pain, an actual pain, then the sort of emotional pain dissipated."

Over-thinking and Rumination. Several participants spoke of repetitive focus on particular thoughts or issues as a response to perceived lack of control played a part in the development of their emotional difficulties:

> P5: “I think there's always a danger that when you try to ruminate over things that are not with your control, it can cause mental harm”.

> P2: “Maybe it was harder for me to, to get rid of negative thoughts because the autism made me focus on them”.

One participant actually linked this to the development of self-harming as a way to cope.

> “What is wrong with me? Why am I always… I was always sort of ruminating and overthinking about what conflicts might occur in the in the workplace. It was quite terrifying and I'm a big lad, but autistic people tend to be quite pacifist and I am. But when people look at you on the outside, they see a big lad. That’s how they treat you. It was chaos and terrifying, so I was going to the doctors because I started self-harming.”

Impact of Alexithymia. The participants spoke of a range of experiences of alexithymia in relation to their mental health. For some, alexithymia made it difficult for them to know how to respond to their emotional difficulties:

> P9: “I just didn't instinctively know what these emotions were.”

> P8: “I didn't know what to do with these emotions, I didn't know what they were trying to tell me or what they even were… It was just a constant struggle because, you know, it was like being bombarded with something you didn't understand every day.”

For others, alexithymia meant that they related to their experiences differently, and this made it difficult to engage in therapeutic support for their emotional difficulties:

> P7: “I know so, so, so many autistic people who have felt that CBT wasn't helpful, but maybe the other types of therapy were much more helpful and that was nice for me because it was CBT that I did with my therapist, and it always really frustrated me because I would go and like she would ask me how I felt during the week. And firstly, I didn't know how I felt because like I'm not feeling anything, I don't know.”

Whilst another participant found that learning about their alexithymia helped them to understand why they were having difficulties managing their emotions:

> P9: “All the other things that I'd been diagnosed with previously and what came with that was alexithymia, which is, you know, not understanding those emotions. So, it was really quite an eye opener for me to realise that actually it wasn't my fault, but that I could learn it. You know, it's something that I should have been taught when I was a child but wasn't.”

1.3 Intersection with Identity

The intersection of being autistic with other aspects of identity was a topic of several interviews. This was discussed by participants as a mixture of additional challenges and sources of strength.

Gender. One participant spoke about the additional challenge of identifying as transgender as well as autistic, particularly being a young person before these identities were known or understood:

P15: “So I didn't know what trans was until I got done with autism, so I was about 15 and then within a couple of months by about the age of 16, I was fully out as with a different name and pronouns, I think, which probably shows the power of young people actually knowing what these entities actually mean, because if we don't know, then we're just going to think we're aliens.”

A female participant spoke of how being autistic can be experienced differently when you are female, resulting in increased masking:

P5: “I have spoken to a couple of other people on the spectrum, and they have said that women are very underdiagnosed, and I think women are also much more of umm, stressed” … “I think generally I've probably been able to integrate much more easily and in a lot of ways and into different social situations and then others. One of the key things though, women are better at masking, or women are better at, in terms of like their special interest, they tend to be a little bit more like mainstream. So, it’s a little bit harder to detect.”

Another participant spoke about how stereotypes of women influence how they mask their emotions:

P9: “I'm very conscious of potentially being labelled as overemotional, overdramatic” … “So, there are times where I'm interacting with colleagues and I'll be like getting kind of pissed off and I'll just take a moment and be like, okay, I can't respond emotionally, which is weird because I've seen men get away with being absolute, like, assholes all the time. And in terms of like hiding my anxiety, I think I do that a lot more at work than I think some of my colleagues do.”

On the other hand, a male participant spoke about how in light of women being underdiagnosed, it now feels as though the majority of resources are aimed at them, and it was difficult to find resources on the male experience of autism:

> P10: “98% of what I see on YouTube is aimed at children and women. And the reason the women thing I understand it completely is that for years and years and years, women weren't recognised as ever having autism. Ridiculous now because it's been recognised and now it’s gone the other way.”

Age. Participants spoke about age and how this intersected with autism and their mental health. In particular, participants spoke about finding it harder when they were young. One of the reasons is that they had not yet developed flexibility:

> P10: “When I was little - I've grown up and I’m more, much more flexible, much more understanding. But when I was little, it was “if something's wrong, it's wrong”.”

Likewise, an older participant reflected on the benefit of age, in terms of the knowledge they had acquired and how this helps them to cope in new situations:

> P13: “You know, sometimes you just have to, put what you've done before into practice in the new situation and learn, learn from experience, which I'm lucky enough to be able to do because of my age, you know? So, I mean, I feel quite sorry for uh young people, especially teenagers who don't have the experience and don't understand why they're getting into this situation. And then, of course, what's happening is that they get angry.”

Religion/ Faith. Participants discussed their experiences of being autistic and practicing a religion. Several participants spoke of how religion had been a source of strength:

P1: “I've got God behind my back.”

Faith and engaging in prayer were coping strategies during times of upset that allowed a participant to feel understood:

> P4: “Obviously, when you're little, we would pray at the end of school. You know, you put your chairs on the table, the arms, put your hands together. Talk to God. Basically, I'm doing this at home, I’d kneel up on my bed and just do that. If I was upset. Oh, talk to God, because I don't think anyone else understood.”

Another participant spoke about how the structure of their religion was particularly comforting when they found uncertainty and inconsistencies difficult:

> P8: “Growing up, there's ‘bad for you’. “Don't have potatoes, fat”. And then they said, oh, no, you know, sometimes they say, “No, they're absolutely good for you. They’re carbohydrates. They're fine.” It's just, I know that's a physical example, but it's the same with everything. People's opinions are subjective to them, whereas religion… it wasn't that. It was more concrete and that was comforting.”

Culture and Ethnicity. One participant discussed how the values of particular communities can intersect with the experience of being autistic, particularly in cultures that value privacy. This had increased their tendency to engage in masking behaviours. In this example, the participant spoke of West Indian Communities:

> P3: “Within my culture, everything's supposed to be private. Everything's taboo to talk about, and that means everything's hidden. Which meant too, because I had to hide things, I learned very early on how to mask.”

This also extended to South Asian communities:

> P6: “In a lot of East Asian culture, there's a lot of stigma over mental health issues. So, you don't really talk about it very openly.”

Cultural values can impact on individuals support networks as it impacts how much mental health difficulties are spoken about:

> P10: “When I was a kid, like hiding a lot of mental health issues or like, not being able to talk to my parents very easily about it versus like I see my sister-in-law who like talks openly about her anxiety issues”.

Other participants spoke about the additional challenge of intersectionality with marginalised identities, such as being a black woman:

> P3: “It's the emotional labour of explaining that emotional labour and, you know, not only do I have emotional labour whenever, you know, as a Black woman, there's an intersectionality that comes into it as well, as I'm a Black neurodivergent woman.”

Or being of mixed- ethnicity, and not having a sense of belonging:

> P8: “That's kind of been a constant in my life because… a lot of things growing up. I never fitted in anywhere. I'm not white, Caucasian, European. I'm mixed race, so.”

Parenthood. One participant spoke about the experience of being an autistic parent, particularly to also autistic children, and how they did not feel adequately supported:

P12: “I think if I look back on it now, there are lots of life experiences that we could support autistic people with. You know, particularly, you know, becoming a first-time mum, things like that.”

P8: “I mean, my child is adamant that they don't want children because of their autism and that is a twofold thing. Firstly, it's because they feel that they couldn't cope with the challenges that it would raise, and secondly, because they actually feel strongly enough that they don't want to pass on what they have because they have struggled so much throughout their own life.”

Another parent spoke of the additional burden of feeling like they had to “battle” to get the appropriate support for their autistic children:

P9: “The local authority does not want to put in place what they need to, and it's taken over everything. As they've got older that has absolutely taken over everything and it's a battle. Every little thing is a battle you're walking on. Not knowing what might happen at any time, you don’t know what's around the corner. They're very, very adversarial. They, you know, despite all the research, you know, that is available and everything that's known.”

2. Interpersonal Factors

This theme encompasses social interactions, relationships, and dynamics.

2.1 Social Selectivity

Participants spoke of the importance of being selective about who they choose to socialise with for the benefit of their mental health:

P2: “And that's something I've tried to seek out ever since; I've tried to be a lot more mindful about people I socialise with and what kind of people I want to hang out with.”

With another participant choosing to end unhelpful relationships for their wellbeing:

P3: “Yeah, I had to get rid of some people that weren't very good for me around me.”

The wrong friendships could have negative effects on mental health and lead to low self-esteem:

P1: “I would have friendship groups and you know, on reflection, they were really bad for my health and my mental health because I had to act a certain way in front of them and otherwise, I'd be deemed weird and stuff like that.”

Helpful friendships included being willing to understand more about autism:

P6: “I found people who didn't know as much about autism but who learned for me to better understand me. And then the people who didn't want to, that's fine, they're gone. I didn't bother with those relationships.”

2.2 The Value of Friendships

Many participants spoke about the value of having friendships. One participant spoke about how their stress reduced when they had a stable friendship group:

P11: “I have a lot of great friends who are great support systems as well, so I think that's a part of it, like removing a lot of those external stress factors that I used to have when I was a kid, a lot of the stress came from like these interpersonal dynamics.”

Having a good friendship group allowed another participant to reduce burn-out caused by masking behaviours and feel more understood:

P6: “I had a solid friendship group who really understood me, so I didn't have to mask in front of them and go home, burn out from masking all day and stuff.”

Another participant spoke of how being accepted in a friendship group helped to boost their confidence and led to self-acceptance:

> P1: “My friends really helped. I think they were the main factor [in my mental health improvement] because in secondary school I didn't have any friends. It felt nice to be accepted by people. Which really helped me be more confident in myself. Because then I started accepting myself too.”

2.3 Connecting with other Autistic People

Participants also spoke about how valuable it was to connect specifically with other people who identify as autistic. One participant said this was a key part of their mental health improvement:

> P2: “Before that, I wasn't really that active in the autism community, but it really has helped me to feel better.”

Another participant shared that it gave them a sense of solidarity that they were not alone with their emotional difficulties:

> P1: “I've joined a couple of autism societies in the area, and I do meet people there and I feel like they understand me better than other people. That’s very important for me. It makes me feel like I'm not the only one dealing with these issues. Because the feeling that you're alone with these things can be really devastating.”

They went on to speak of feeling a sense of affinity and belonging with other autistic people:

> P1: “I realised after that that autistic people do have an affinity with each other and can detect each other quite quickly.”

2.4 Social Mismatch and Misunderstandings

Participants spoke about the negative emotional impact of social misunderstandings. The social mismatch of communication styles with neurotypical people was a threat to wellbeing. For this participant, it would lead to being disrespected by others.

> P9: “I can give you hundreds of examples where, you know, doing whatever I was doing, not having any idea that I was upsetting everyone around me. People would tell me “Are you an idiot?””

Another spoke of how social situations had even been part of the development of their emotional difficulties:

> P7: “I recognise now that it's the reason I get stressed in the first place is because it's a trait of being autistic that you don't easily mix with other people.”

Neurotypical social activities such as icebreakers were named as a specific example of situations that were exceedingly difficult for another participant:

> P13: “You know that thing where you get people sitting around in a circle around the table and they say, “let's go around the table and introduce ourselves to everybody”? God, that’s an absolute nightmare.”

Another participant identified that this ‘social mismatch’ was prominent in the workplace, and therefore they found it helpful to reduce their working days in order to improve their wellbeing:

> P11: “I only work three days a week now, so I don't have to do it constantly and it's nice not having to do that. But you know, it's just difficult because you don't get what's going on. I don't get what's going on in the workplace because everyone sees me as quite serious. I don't get jokes or if I do, it's because I've had to rethink it. So now I just find it's probably easier to not even try and interact. I'll go for a walk for lunch instead so that I'm not actually putting myself in that position where I feel like I'm sat on my own again.”

2.5 Vulnerability to Mistreatment

Some participants identified a major threat to their wellbeing as being treated badly by others. For one participant, they felt as though others would “drag them down”. They also recalled painful situations in which they had been treated poorly:

> P1: “But you know, being told to shut up is the worst thing. Umm, you know, being told to shut up when you want to talk and then then I was suffering in silence, sitting there. That was the worst.”

Another participant spoke of how social differences that are characteristic of autism meant that they found it difficult to identify when a social relationship was abusive, and this made their emotional difficulties worse:

> P14: “I had a few relationships, I think, which were, I would say, abusive, but because you're not really very good when you're autistic at being able to measure things properly, you kind of put up with it and that kind of exasperates the emotional problems.”

Bullying was also common in childhood for many of the participants.

> P9: “And I was getting bullied at school really badly as well. And I just didn't fit in with the other kids, so that I was always getting called weird and I didn't know how to just get on with people. So, I was always falling out.”

3. Environmental Factors

This theme encompasses factors related to the surroundings or wider environment that the individual is in.

3.1 Societal Lack of Understanding

Participants spoke of the negative impact on their wellbeing due to a societal lack of understanding of autism, and how this translates to a lack of adaptation and acceptance. For this participant, it is an alienating experience:

> P10: “Most of them have no clue, so you'll explain to them, and they are looking like you are literally from another planet because they don’t get it. And I don't blame them, because if they don't have someone in their circle that is on the autistic spectrum and know how to classify that, they don't have any framework of reference”.

Another participant spoke about how society accepts neurotypical ways as the norm, and therefore those with autism are expected to adjust:

> P11: “It's almost just expecting me to make the adjustments rather than them.”

This lack of understanding is also reflected in workplaces:

> P14: “I mean the outside world is by its very design, at least society is quite abrasive. And so, for example, I've got really bad issues with executive function

and like at work sometimes I'll get like people who are short and irritable towards me."

It is also reflected in educational institutions:

P15: "It wasn't like a very positive environment, but I think also maybe because they weren't used to handling umm, people with autism who have mental health difficulties, I don't know, because I found mainstream particularly isn't fun for people with autism."

This was echoed by another participant who struggled in secondary school due to a lack of autism awareness amongst education staff despite receiving an autism diagnosis.

P6: "In secondary school the students, nobody, was educated on it, like not even the teachers" … "because I was diagnosed and because not many people were educated on it, I struggled a lot."

3.2 Barriers to Support

Participants discussed some of the barriers to accessing mental health support. Several spoke of being discharged when they still felt as though they needed further support. In fact, one participant found that once they were diagnosed with autism, it became harder to access mental health support.

P15: "A psychiatrist or whoever says, "Oh it will open doors for you". And it's like... Where are these doors? One emotional well-being team said they were gonna do one to one with me. And then [I got the diagnosis]. They basically said, "uh, we're not specialists in autism. And now that you've got an autism diagnosis, we're gonna have to discharge you." And that was that."

This experience was shared by another participant, who seemingly was treated as if mental health difficulties and autism were mutually exclusive:

> P4: “At the minute I got the diagnosis, CAMHS discharged me. Then on the grounds that I was autistic and not mentally ill.”

Another participant struggled to access support for many years, then was discharged prematurely due to perceived social support:

> P3: “For 15 years I was asking for this help, and nobody helped me. Even a crisis team had said they would help me and at the time I was going through really serious problems, and they turned around and said, “Oh well your family are supporting you now, so we're gonna discharge you.””

Long waiting times also prevented another participant from getting support for their emotional difficulties when they needed it most:

> P3: “I got referred to an eating disorder clinic and the nurse practitioner saw me within six months, then told me I'd have to wait another six months. But actually, I ended up waiting for another 18 months. By then I could have been dead.”

3.3 Mental Health Stigma

Participants discussed the negative impact of mental health stigma on emotional wellbeing. This was present on a wider, societal level:

> P5: “Well, I mean when it comes to mental health in general, I just think that it's unfortunate that in this country we have a problem with mental health, it is not viewed in the same way as physical health.”

It was also present on a family-level. Mental health stigma influenced how one participant was responded to by family when they shared that they were experiencing emotional difficulties:

> P4: “Over the years I'd said to family members and some of them were angry. What have you got to be anxious about? What have you got to be low about?”

3.4 Housing

Participants discussed how ongoing difficulties with housing maintained their emotional difficulties:

> P9: “It’s a lot harder to get better in an environment that maybe you've got it in in the first place.”

Specifically, being in a noisy environment was difficult for one participant with sensory needs:

> P11: “I've always struggled with people shouting. I can't hear people shouting. And I’ve had that issue with neighbours. Just very, very noisy, aggressive neighbours. It’s that causing all the problems.”

Although they currently had a suitable living environment, housing continued to be a threat to wellbeing for this participant due to worries about housing security in the future:

> P11: “I'm just terrified of what's gonna happen to my mental health if they decided we can’t stay here.”

3.5 Sensory Environment

The sensory environment is particularly important for some participants:

P5: “Explaining what the default is to people when you walk into a different room. You're just overwhelmed. All this information flying at you, you know, so many things, and the last thing you notice in the room is the other person.”

For one participant, their sensory needs were a part of the development of their emotional difficulties as a child, as they would often feel overwhelmed in day-to-day life:

P6: “I do things differently and have specific things that I like and things like that, and then I would get overwhelmed a lot as well because I don't really like loud noises. But in a school, it was just full of loud noises.”

Being aware of sensory needs was a helpful way to counteract the impact on wellbeing:

P3: “I can say, OK, well, yeah, I'm feeling anxious because I've gotta go to a meeting and I know the lights are gonna be really bright. And I forgot my glasses or something like that. I can actually identify the feeling and not feel ashamed about it.”

Several participants had developed ways of managing their sensory needs to support their wellbeing:

P2: “I think the big things are like remove myself or like not trying to force myself into situations that are just not working from me.”

P13: “So, I when I look back, I can see that I've looked at a situation, realised that I'm not comfortable with it and engineered it so that I'm not put in a position where I am not comfortable with it.”

3.6 Accommodations

Several participants spoke of the importance of accommodations being made for neurodivergence. The provision of such accommodations was a factor of maintaining emotional wellbeing. However, for many, the lack of accommodations being made continued to threaten their mental health. A participant highlighted the positive effects of accommodations:

> P10: “And in very rare occasions they will ask what accommodations they can do, which is so you know, *so* good for someone. Finally, someone says, OK, I understand that you are thinking differently. How can I help you?”

Participants found it helpful to have allocated quiet spaces that they can go to, particularly when there may be sensory triggers. One participant spoke of small changes that were made to ensure their volunteer role was accessible:

> P2: “Yet there are some things we can do, but they're rather small things I think, like on the place I do my volunteering at it's a really quiet location and there aren't too many people over there. So that's a really good sensory environment for autistic people. So, if autistic people could have something like that, umm, that would be great.”

Another spoke of helpful accommodations in a school setting:

> P6: “In biology, whenever they had to, like, demonstrate something sensory, they would always give me a heads up. I’m about to make a lot of noise. Do you want to leave? And they would let me use my fidget toys.”
>
> “It helped [in college] when they gave me quiet places to sit and eat my lunch instead of in the canteen. Before that in secondary school we weren't allowed anywhere else, more because of like safeguarding and stuff because, you know,

they need to know where I am and stuff. But in college I could leave when I needed to."

However, one participant spoke of the challenges of accommodations being consistently implemented in the workplace, and the burden of needing to remind others:

P12: "Even though I've got a very inclusive workplace, they've just started a neurodiversity group, which I'm part of. I can be very eloquent sometimes in explaining what I need, and they go, "Yeah. Yeah, yeah, yeah." And then just completely forget about it and carry on as it was before. And it's very, very difficult to keep sort of saying but… but… But I need this. I need this. I need this."

3.7 Access to Resources

Participants spoke about the value of having access to self-help and wellbeing resources. Many found these through the internet and online spaces:

P3: "I'll go on Eventbrite and look for things. I type in 'anxiety breathing' or them kind of things and I'll go and do them."

P6: "I found an Instagram account that I found that breaks down autistic traits into, like, really simple words and I would just… I would always recommend that."

P8: "It's knowledge acquisition. Up skilling. I mean, I do some of that anyway through the Internet, you know. So, for example, when [my autistic children] were going through that experience, acute trauma at school, I was reading up about that."

One participant spoke about the difficulty of not having access to resources, such as local autism support groups, which they believed they would find beneficial for their wellbeing. Online spaces appeared to be a solution to this:

> P12: “I think it would be great and I'm sure there must be other people around where I live, but there are no groups that I'm aware of and I have looked quite extensively, and I think it would be great to have that. The only opportunity I get to talk with anybody is when things like that happen online.”

4. Strategies and/ or Support

This theme captures different approaches to improving wellbeing by engaging in groups, interventions, support services, or using self-management strategies.

4.1 Diagnostic Experience

The process of diagnosis in itself had an impact on wellbeing for some participants. However, there were mixed experiences of the diagnostic process as a positive or negative experience for different participants.

Diagnostic Process Experienced Positively. One participant explained the clarity and self-awareness that an autism diagnosis allowed them, and the subsequent positive impact this had on their wellbeing:

> P9: “Being out all day doing this that and the other, but because I didn't know I was autistic, I didn't know why I felt so bad. And then I would start to feel so depressed because, oh my God, I feel terrible. And I thought, “what's wrong with me that I'm so affected after this?” So, then I start having self-loathing. So honestly, I think the turning point for me in my mental health was actually to finally get my diagnosis at first.”

Another participant outlined specific aspects of the diagnostic process that they found helpful, namely speaking with clinicians who had experience and knowledge of autism and/ or working with autistic people in a neuroaffirmative way:

> P7: “I was really grateful for it because you can tell that they work with and speak with autistic people and also a lot of the staff were autistic as well. They were really good at explaining that they see autism as a difference rather than a deficit”.

Diagnostic Process Experienced Negatively. Other participants, however, found aspects of the diagnostic process challenging. Some found the assessment to be too brief and it therefore not feel comprehensive or holistic enough:

> P5: “And like quite short, it was like, I think an hour, hour and a half, for the whole diagnosis. I didn't feel that she really took the time to dig deeper into a lot of things. I think she was just like ‘check’, like going through a checklist almost.”

Three participants spoke of getting alternative diagnoses of BPD initially, which was later confirmed as autism. As may be expected, they did not feel the BPD diagnosis was accurate for them. One participant in particular, was given three alternate diagnoses before arriving at an autism diagnosis, and spoke of the negative impact this had on their relationship to help as well as their overall wellbeing:

> P14: “It's kind of like, no, we're just going down another one, and that was the point that I kind of withdrew from getting any help because I've felt that the help that I was trying to get was making everything worse.”

One participant highlighted the negative experience of late diagnosis, and how this was experienced as traumatic due to the number of years spent without an understanding of why they felt different from others:

> P5: “It was not very validating I guess because... I mean before that it would be [name] is [name]. Then it’s “have they got learning disabilities or have they got…” uh like there's all sorts of stuff thrown around really and I think I just felt like I was just weird for no reason almost. So, I think being late diagnosed with autism is something that maybe people don't think would be as traumatic as it is.”

4.2 Self-Management Strategies

There were a wide range of strategies that participants reported utilising in order to achieve improvements in their emotional wellbeing.

Healthy Habits. Participants spoke of ensuring that they engage in healthy lifestyle habits such as eating healthily, exercising, and getting more sleep.

> P11: “I would suggest going to the gym (even though I struggle with the motivation to go) but the feeling that I've got after I've done it is fantastic.”

> P5: “I think it's very important because I can tell the difference in my headspace if I've worked out that week or if I've just been stuck inside an office building all week.”

> P3: “I said I want to start cooking from fresh. And so, I started doing that. It took a few months to get into a steady roll with it.”

Reducing Demands. Participants spoke of the value of reducing the demands placed on them when they are feeling overwhelmed. For one participant this involves recognising when work roles may be too demanding:

P7: “I tended to go for quite challenging roles, but then when you go for challenging roles, your expectation is for you to conform and perform a certain way, and I can't do that.”

Other participants spoke of using time management and organisation skills to ensure they plan their time in line with their needs. For example, ensuring there is enough time to decompress in between activities.

P12: “I manage my activities better than I used to and I understand better now what triggers me.”

P9: “I need to literally not do anything in the evening and just, you know. Play a game or read some information or watch some YouTube or things like that.”

P12: “So being organised, which is one of the traits of my autism, means that I can avoid stress as much as possible, not necessarily 100%, but as much as possible”.

It was particularly important for many participants to reduce social demands by making sure they had enough alone time:

P10: “Might seem selfish, but I like being on my own because it means I could choose to go out and see other people when I want to. I get a little bit of time where I can, you know, reset. Then I can do that without anybody intervening.”

P14: “People used to get worried when I isolate myself. But actually, even to this day, I would say that a lot of the time it was the best thing for me because I would be overwhelmed. I’d feel overstimulated and what would make it worse is that somebody else didn't see the fact that I was overstimulated and

came in and raised their voice, and that the voice was 10 times louder than they realised. And it's like: Right, I'm out now. I'm walking for 10 miles."

P5: "I'm pretty well, so I think one of the key things that I tend to do is when things are like quite emotional, overwhelming and things I just need to like put myself separate from everything that is happening. So, I just go away somewhere alone and then kind of shut off for a bit."

Routines and Planning. Some participants emphasised the importance of maintaining a consistent routine in order to reduce stress arising from unpredictability:

P11: "I don't know what it's like not to live in a routine. I've lived my entire life in a routine, so I can't imagine the idea of doing something at the drop of a hat. I mean, it's just totally alien to me. No, no, I can't be doing with all that. I mean, I don't wanna be in a strange place, you know?"

One participant discussed how planning helps them to prevent depression:

P5: "I have a big wall banner on the wall and this friend of mine. She said to me, "why do you have a wall planner on the wall?" Because I like to put everything on here, I have it on my phone, but I like to have it on the wall written there so I know it's exactly what's happening at any given time or what's happened in the past that I need to keep note of." … "A lot of people find this all mad, but you know, for me it's great because it means I don't need to get depressed."

Whilst another discussed how planning reduces their anxiety:

P11: “I didn't realise this was weird until a friend pointed it out, but I'm hyper organised when it comes to managing my schedule and I thought that was just part of being a normal professional. I have a calendar that has hourly, half hourly schedule notes, to do lists and monthly schedule, yearly schedule. I get one every year and on Sundays I sit down, and I plan out the whole week. In terms of everything that I need to get done and that. And actually, sometimes when I'm feeling a bit anxious or stressed, I just sit down and make lists of things I need to do, either like professionally or personally or whatever it might be. And that calms me down.”

This was echoed by another participant:

P12: “I think a part of it is that sometimes the anxiety comes from having way too much, like balls in the air in terms of juggling a lot of things. But by putting it, writing it down and saying ‘OK, this one is on my to do list for next week.’ I just completely can forget about it knowing that I'll pick it up next week. And so, for me, the pretty crucial part of my coping strategy is probably just like having a very robust scheduling system.”

Self-Help Mood Strategies. Participants spoke about some strategies they applied to help identify and improve their mood. For example, one participant discussed the value of using breathing techniques when feeling anxious:

P14: “One of the things that was really profound for me was that anxiety feels like such a bottomless pit. The worst thing about it is the terrifying sense of lack of control that you've got over it because it could just come out of nowhere and if it's prolonged and lasts for long enough, it just smacks you in the face sometimes. I practiced using breathing techniques. Even just simply,

> the belly breathing is a good one. I found that I could reduce it from an 8 to a 6 and that was mind blowing to me cause a sense of control is something you don't usually have."

Other participants found it helpful to intentionally research psychoeducation about emotions in order to understand themselves:

> P5: "I always kind of had trouble like identifying and teasing out what emotions that I'm feeling at the moment, but that's why I, uh, intentionally kind of studied it and was like, OK, this is what I'm feeling now, and this is how it manifests itself for me. And that's how I'm best able to deal with it."

Another participant used a similar approach by purchasing 'mood cards':

> P12: "So, I actually bought myself some mood cards. I spent a whole year each day, I would get up and I would get the mood cards out and I would work out what I was feeling."

A different participant used a self-help app as a space to recognise moods, practice mindfulness and express themselves:

> P3: "And then I found an app. You can circle words about how you're feeling, and then it does this thing with meditation. You can write about it as well. I found that by the time you're finished writing about it, you've got it all out and the anxiety you were hold onto has been released."

An alternative strategy used by another participant was to use imagery and daydreaming as a relaxation strategy:

> P8: "Randomly daydreaming in quite intense detail, about things that were interesting to me. And it will sell out from the general hustle and bustle, the

noise, which is too much and just to make it easier and calm. It's calming. That's because you've created your own bubble and your own bubbles amongst, you know, 30 odd other people. So, it's yeah, quite good to be able to do things like that."

For another participant, this involved using sensory strategies/ engaging in stimming behaviours, such as using fidget items:

P12: "I have my spinner ring to destress me which I use even without thinking about it throughout different times during the day."

Special Interests and Hobbies. Participants discussed the importance of regularly engaging in their special interests and hobbies for their wellbeing. These hobbies varied widely, such as building Lego, lorry spotting, music, reading, swimming, and gaming. The commonality was that engaging in their preferred activity allowed them a sense of enjoyment and achievement. One participant illustrates how their Lego hobby improves their well-being:

P6: "I could just sit and just quietly just build stuff and then when it comes to the final piece, it's just this... I've created something that looks so cool. It's so rewarding. I can hear all the clicky noises of the pieces clicking together, and I can just sit and then just do that for hours. It's such a nice feeling."

Another participant commented that believed that had they been "allowed" to focus on and pursue their special interests, they would have thrived. Seemingly as they felt pressure to conform rather than follow their strengths and interests:

P11: "But if I was allowed to focus on music and teaching music, or technology, I would have flew. But I didn't get opportunities unfortunately, that sort of thing. I thought this is not the world for me."

Volunteering. Some participants had found it valuable to become involved in volunteering, as it gave them a sense of meaning and purpose:

> P2: “I joined some autism societies and I also do some volunteering for those, and I find that really helps. It gives meaning to what I do. To me it makes me feel like the things I do matter.”

For another participant, it met a number of needs such as having alone time, keeping active, and spending time outside, whilst still being rewarding:

> P11: “I do a lot of volunteering work and that was helpful as well to keep me occupied. I go litter picking around the local malls. It's something very active. It's just nice to get out. Sometimes I need to get away from people. And I’m actually doing something useful.”

4.3 Experiences of Therapy

Participants discussed therapy they had engaged in to improve their well-being. Therapies mentioned included CBT, DBT, ACT and mindfulness. There were no specific therapy models identified that were experienced more positively amongst the participants than the others, instead it varied person to person. Key elements of therapy were discussed:

Demands of Therapy. Participants spoke of the demands of therapy. Several participants spoke of alexithymia, and the demand that was placed on them to formulate their thoughts and feelings. One participant discussed this in relation to DBT:

> P15: “DBT is very much sort of chain analysis based and my brain doesn't sort of work like that. So, like you have to write down sort of thoughts, feelings,

emotions, physical sensations and the other one for me then is physical sensations that I don't understand particularly."

Another participant who engaged in CBT discussed the demand of completing home practice tasks, and the guilt that surrounded not completing this:

> P6: "The homework review, especially if you're an autistic person, because we can be very completion-oriented sometimes, and it's like if we're on a low ebb and you're giving us homework, now we're gonna deal with the guilt of not doing it if we didn't get a chance to do it. And that's not what the therapist wants, but that's what you're gonna get."

Practical Coping Strategies. Participants found it helpful when they gained practical coping strategies, as this gave them a sense of regaining control. In this example, a participant speaks of engaging in DBT:

> P12: "In those moments where I hadn't learned the coping mechanisms just holding, say, a piece of ice in my hand until it hurt, it didn't give quite the same response, but it broke the cycle. And so that was the starting point of, you know, the baby steps of being able to bring some control back to me."

Change in Outlook. One participant spoke of finding resources they could read independently about the Acceptance and Commitment Therapy (ACT) approach useful. They reflected on how this changed their outlook:

P14: "That had a profound impact. I don't have any expectation around a happy life definitively, and it's just that the way I am now gives me the optimism to see beyond the suffering and the difficult aspects of life and to be more pragmatic towards and what I do about changing the difficult situation."

Social Strategies. One participant found the structured approach of CBT helpful for practicing social skills, but felt that this was geared towards neurotypical behaviours:

> P3: “I asked my therapist to teach me, and we did a lot of cognitive behavioural therapy where, for instance, I’d identify situations where I could practice. For example, I'm talking to a cashier at the store or just doing some chitchat or trying to monitor my eye contact or other forms of nonverbal behavior, and just really trying to improve those things and trying to do these things as a neurotypical person would do. But I never really felt like I got good at that either. I think it may have helped a bit. I did acquire some skills and it it's I certainly learned a lot about human behavior and it's it made me understand why some people do what they do.”

Another participant who had similar experiences of CBT exposure therapy in social situations had a more negative experience. They highlighted the “exhausting” nature of it, also in reference to neurotypical social norms:

> P2: “It was the kind of thing where I go practice social situations and things like that and I then started thinking that this was rather detrimental to my health because it took a huge amount of effort, and I didn't really gain very much out of it.”

Therapeutic Alliance. Whilst there were mixed opinions on the most helpful models of therapy, there was more consensus between participants on traits of the therapist and aspects of the therapeutic alliance that were significant.

Scepticism vs Trust in Therapy. Participants spoke of the importance of having trust in both their therapist and the potential for therapy to be effective. One

participant spoke about how understanding the evidence-based rationale for the approach allowed them to trust and engage in their sessions:

> P14: “So, learning about neurology, learning about psychology, that give me the ability to trust that these things might work for me. And so, in developing that trust, that's when I would engage in the psychotherapeutic interventions offered to me and the ones that I've learned. And that's when they began to work.”

On the other hand, another participant discussed their negative perception of the efficacy of mindfulness based on their own experiences and speaking to others, perhaps highlighting the need for a clear rationale behind the therapeutic techniques:

> P2: “I've seen research claiming that this this really does help autistic people, but in my experience a lot of people act kind of allergic to this kind of these kind of exercises and it's just it kind of comes across as bull**** to them. I'm not sure if that is something that should be done with autistic people, or maybe it should be done in a different way. Maybe a logical thinking autistic person more easily has all these thoughts of reasons why this couldn't work.”

Trust in Therapist. It was important to participants that their therapist had knowledge and understanding of autism, and were able to provide therapy that was delivered in a way that is suitable for neurodiverse people:

> P15: “Autism as like another layer to mental health, and I think there's not many practitioners around or really any that I've met properly that seemed to actually have been given training to know what that distinction is and how to work with that. You give this person homework to do and say, oh, it's because XYZ. If they don't think XYZ's an important reason to do the homework, they just won't do it.”

Validation. Therapists who were described as “validating” were unanimously perceived as more helpful and supportive. One participant described how they did not particularly like therapy, but did benefit from the validation:

> P15: “But I think you know the therapists that I have preferred to work with, cause I've never particularly liked therapy much, but the ones I preferred to work with are the ones that which sort of validate and say that like, “yeah, most people might feel this way. But you know, if you feel that way, that's perfectly okay”.

Another participant spoke of the significance of a therapist providing validation in the context of the autistic experience of frequently feeling invalidated:

> P3: “It's being able to challenge those thoughts, but also not feel the therapists are invalidating us for feeling those at the same time. I think invalidation throughout life can be really harmful. And almost like traumatic in its own right to feel that you're invalidated all the time.”

Person-Centred Approach. One participant spoke of the negative experience of not trusting in their therapist’s competency due to the therapy not feeling personalised enough:

> P10: “She literally had some scripts, and she was trying to apply those scripts step by step and I’m the wrong person to apply scripts to. I’m not the kind of person that will tell someone to their face “you are incompetent”, but it was one of the rare situations where I had to tell.”

Given the heterogeneity of autistic people, many participants agreed that such “blanket-approaches” were seen as unhelpful:

P7: “I think there's a very blanket approach to mental health which doesn't help. It’s good that there is some kind of help, but it would be nice if here was a little bit more acknowledgement of the fact that that's not necessarily gonna work for everybody because when it feels like everybody's given the same advice or given the same type of support and then that support doesn't seem to work for you, it can feel very much like, well, that's the help, but it's not helped. I’m never getting better.”

Neuro-Affirmative Approach. Participants disliked therapy that had neurotypical assumptions and goals. Some participants actually described how this had been harmful. For one, it was psychoeducation based on neurotypical behaviour that made them feel abnormal:

P15: “It was to the point where it was like, the therapist is saying to me, “the human brain works like this”, but really, they meant the neurotypical brain works like this. And I don’t agree. But like they say, “and then your brain goes from this to this” and I just it… I felt really kind of like, “Oh my God” at a certain point, I convinced myself well, my brain convinced me that I wasn't human at one point. Because I could not relate.”

For another participant, it was having goals based on neurotypical behaviours:

P2: “I saw a therapist and we tried to – I really wanted to be neurotypical – so I tried to train my social skills and non-verbal behaviour, and I very much tried to be just like a neurotypical person. In the end, that was also very damaging for me, and perhaps one of the distant causes leading to my breakdown in 2020 and ever since I've tried to see my autism in a more positive way, and I've just tried to be myself more.”

Another participant spoke of the intersectionality of being autistic and experiencing anxiety, and why it was essential for therapists to consider both aspects:

> P15: “I didn't really feel like there was a lot of knowledge about autism, and that was a problem for the way they approached it. It was like they were treating me like another person with anxiety or depression, but they should be treating me like an autistic person with depression or anxiety. The advice that's given doesn't always apply to you, because when they say, “people like you should go out and meet people, that's good for your mood” and it's not taking into account that for autistic people, that can be an additional stressor.”

On the other hand, one participant discussed how a therapist considering this intersectionality had worked well for them, by having liaison between the clinician that had completed their autism diagnostic assessment and their therapist:

> P9: “I had this one after my diagnosis where the people who supported my initial assessment of autism, they spoke to my therapist before my therapist started the therapy with me so that it could be tailored. And it was the best therapy I've ever had. Weekly I make the time when I go to it because I know it's gonna be aimed towards me, that the people that I'm talking with are gonna understand me and my needs.”

4.4 Support Beyond Therapy

Several participants spoke of other forms of support and/ or professionals they had engaged with that had helped to improve their emotional difficulties, other than psychotherapy/ therapists. These are outlined below.

Academic Focus. Participants received support from other professionals as well as therapists. One participant shared how they had received well-being support from an academic tutor, who helped them re-focus when they experienced anxiety:

> P5: “My mother hired me an academic consultant to work with, and she kind of became my defacto therapist, I guess, because I loved her. She was such a lifesaver. And because of the way I dealt with my anxiety was just to keep myself busy and spread myself super thin and then burn out, and then I would get in a weird, vicious cycle of it. She helped me stay much more focused and say, “OK, what's your goal? Let’s work towards that.””

Advocacy. One participant spoke of how involvement in advocacy groups has benefitted their mental health, by engaging in a values-based activity that has the potential to create meaningful change:

> P15: “On my own, I may not be able to, you know, change the law or policy but actually if it's people that actually agree with me and we all come together we have a stronger chance and I think finding advocacy groups and actually even just knowing that they exist is really nice. I suppose it's like my version of a support network. It’s not a support network for me it's a support network for supporting people’s rights and things like that and I think positive change and positive action is something I feel passionate about. It’s nice and it makes me feel positively about the world.”

Coaching. One participant spoke of preferring coaching rather than therapy, believing it is better suited to autistic people due to the Socratic, solution-focused nature:

P12: “I think that coaching is far better for autism than therapy because therapy tends to be “oh, what don't you like?” and you're going over it rather than finding a solution to it. So instead of giving people coping strategies all the time, that will work for some but won't for others, coaching I think is brilliant because it allows you to find your own way of coping with it or fixing it.”

Financial Support. One participant described how receiving financial benefits actually allowed them to fund the resources they needed to improve their quality of life. In particular, receiving PIP payment meant they could afford a car:

P12: “One of the chapters of me being so depressed before. I didn't have a car and I really struggled with public transport because it's just, you know, unpredictable. We struggled with going out and I would go out and I would be absolutely exhausted by the time I came home. When I'm exhausted, I get overwhelmed and then I can’t deal with the noise or anything. I ended up getting PIP and a car and that honestly changed my life. Like, I finally have independence and freedom. Now I’m able to live a normal life.”

Local Community Services. One participant identified particular local services that were experienced as supportive, perhaps highlighting the importance of the wider environment:

P11: “When I was struggling with noisy neighbours, I had a lot of agencies I was involved with. Local police have been brilliant. Housing association have been very supportive.”

Medication. Several participants had tried medication and had found it helpful to manage their mood. One medication that was named as helpful for anxiety in particular, was propranolol:

> P14: “Propranolol, it's like a weak medication, it does just enough to kind of allow me the luxury of a level of complacency in the face of a of a world of chaos.”

Public Speaking Class. One participant found it helpful to attend classes aimed at improving public-speaking skills. However, was in the context of having strengths in other areas, making the experience feel strengths focused.

> P5: “My mother also noticed I hated speaking to people, so she enrolled me in public speaking courses since I was 7 years old. It was a very thorough public speaking course we would have scripts and we would practice where to pause, where to breathe, where to enunciate and things like that. And so, because I got so much of, like, public speaking training since I was a kid, I don't mind public speaking now, but it's definitely not something that came naturally. And I feel very lucky to have had a lot of that support and like without any stigma of, like, “oh, she needs help in that.” It was more “because she's such a genius she doesn't have a lot of like social skills. So, we need to kind of help make up for that”, but it was never like framed in a negative way or anything. And I think if I had been diagnosed a bit earlier, maybe it wouldn't have been such a positive spin on it.”

Discussion

The primary aim of this study was to explore the experiences of autistic adults regarding improvements in anxiety, depression, and related emotional difficulties. By

conducting semi-structured qualitative interviews, the study sought to understand how these individuals define and experience mental health improvement and/ or recovery. The key findings revealed a broad range of significant factors influencing autistic mental health, including personal attributes, interpersonal relationships, environmental influences, and strategies for improvement. These insights provide a comprehensive view of the nuanced experiences of autistic adults. The following section will aim to integrate the themes and highlight a number of areas for intervention and support.

Management vs. Recovery

One of the aims of the study was to explore how autistic adult participants make sense of their mental health journey. It was identified early on that there may be differences in opinion of the concept of ‘mental health recovery’. In consultation with autistic experts by experience, there was consideration as to whether the term ‘recovery’ in itself would influence the pool of participants that would express interest in the study, as there may be some autistic adults who deemed themselves ineligible on the basis that they had experienced improvement but not “recovery” necessarily, as defined by the complete absence of symptoms. The decision was therefore made to recruit for individuals who have experienced some form of self-identified improvement and make this explicit in recruitment materials. Consistent with this idea, there was a strong consensus amongst the interview participants that they viewed their mental health progress as something they learn to “manage” overtime rather than expecting or aiming towards total recovery. This appeared to be particularly relevant to anxiety, perhaps in the context of ongoing sensory and social differences as highlighted in sub-themes in this study. This is also consistent with previous lived experience research in which autistic people experienced “ongoing

anxiety" (DePape & Lindsay, 2015). Given that modern paradigms view autism through less of a deficit-recovery model but more so via a neurodiversity paradigm (Dwyer, 2022), it follows that anxiety that is interlinked with autistic traits (such as anxiety in particular social or sensory environments) may also be viewed as on ongoing occurrence rather than something to be overcome.

Self-Acceptance

A key component of building resilience and coping mechanisms (i.e. an increased capacity to 'manage' ongoing emotional difficulties) identified by participants was self-acceptance. This involved firstly, the importance of understanding oneself via accessible resources on autism and connecting with other autistic people, and secondly, challenging the neurotypical norms and ableism that are so frequently internalised, in order to accept oneself. For example, many participants discussed how they would engage in masking and camouflaging behaviours over many years, but ultimately feel as though they failed to 'live up to' neurotypical ideas of occupational, educational, or social outcomes, and this led them to doubt their self-worth. This qualitative finding supports findings from a prior qualitative study that found that autism acceptance was a significant predictor of autistic well-being, particularly stress and depression, which was suspected to be mediated by camouflaging behaviours (Cage, Monaco, & Newell, 2017). There are a considerable number of studies highlighting that pressure to conform to neurotypical standards through masking and camouflaging behaviours are harmful to mental health of autistic individuals (Cook, Hull, Crane & Mandy, 2021).

Acceptance from Others

However, the personal factors cannot be contextualised in isolation, and caution should be given to locating the emotional difficulty within the individual. The internalisation of neurotypical ideas and self-blame is very much interlinked with interpersonal and environmental factors. Many participants discussed difficulties with the policies and practices in workplaces and educational settings, including a lack of knowledge about autism, barriers to having appropriate accommodations put into place, and social conflicts or misunderstandings with colleagues. In the wider context, a lack of societal understanding of autism and/ or neurodiversity is informing how these institutions function and leaves autistic adults vulnerable to misunderstandings and mistreatment. A relevant concept is the Double Empathy Problem which explores how there is a breakdown in mutual understanding between two people, but this is particularly pertinent between autistic and non-autistic people. Whilst it is a result of differing disposition on both sides, the assumption is made that that autistic person has a social skill deficit, and they are judged negatively (Milton, Gurbuz, & Lopez, 2022). This also explains why autistic people feel an affinity and sense of belonging amongst other autistic peers.

Person-Environment Fit

One of the most striking findings was the main themes spanning across the domains of personal, interpersonal, and environmental factors, which is in line with the person -environment fit theory, which suggests that difficulties arise when there is a mismatch between the individuals characteristics and the environment they are in (Henninger & Taylor, 2012). It is clear that attempts for the individual to change to fit the environment are not feasible (i.e. the psychological harm caused by masking behaviours). In person-environment fit theory, accommodations and changes to the environment are crucial. This aligns with the social model of disability, which posits

that barriers in the environment and society create challenges for individuals with disabilities. Whilst modern perspectives of autism do not view it as a disability and instead as a neurodivergence (i.e. a different neurological cognitive profile), the model is often applied within the autism community to understand how society accommodates (or does not accommodate) neurodiversity (Woods, 2017).

Intersection with Identity

There is a need for increased diversity and consideration of intersectionality in autism research (Cascio, Weiss, & Racine, 2020). This study used purposive sampling to enhance diversity in the sample. Notably, a theme emerged around the intersection of autism with other aspects of identity, such as age, gender, ethnicity, culture, religion, and parenthood. These intersecting identities often presented additional challenges for participants, particularly those from minority groups, such as ethnic minorities or children.

In the context of the person-environment fit theory, it is essential to recognise that social identity characteristics, e.g. gender, race, age, culture, ethnicity, and socioeconomic status, add an additional layer of complexity to how an individual interacts with their environment. For instance, individuals from marginalised groups may have less power to influence authority or their surroundings. Therefore, creating inclusive environments that embrace all forms of diversity and empower marginalised groups is crucial for enhancing population mental health.

Additionally, some aspects of identity can be useful protective factors. For example, some participants spoke of how their connection with their faith allowed to them to have a sense of structure and belonging when faced with a neurotypical world that feels unpredictable and like they do not belong. Prior research has

suggested that religion is regarded as an important domain for some autistic families and that it should be explored as a resource and coping strategy (Hayat et al., 2024).

Limitations

Due to the recruitment strategy, this study may have unintentionally excluded participants who do not access the internet. A research poster was distributed online and shared with autism support groups, but it was not clarified whether physical copies were printed and shared with group members. The initial screening was also completed via an electronic link. Not only is the sample limited to those with internet access, but it may have also recruited a sample who are more likely to have benefitted from autism support groups, seeing as the study was advertised through these channels, e.g. in newsletters. Participants were not only recruited through these groups, as some were also recruited via the Autistica Network, an autism research participation network. However, data was not collected on how each of the participants in the final sample had found the study. This may have helped to recognise how many participants were recruited via support groups.

This study listed having a diagnosed learning disability (LD) as an exclusion criterion. This aimed to ensure the findings apply to the unique autistic mental health experience, however given that there is a high rate of co-occurrence of LD and autism (Rydzewska et al., 2018) it should be considered in the context of intersectionality that these findings may not represent the portion of autistic adults who do also have a learning diagnosis. It may also have been an oversight of the research design to exclude LD but not also consider other neurodivergences that

frequently co-occur such as ADHD or dyspraxia and that these conditions may have also influenced participants experiences of emotional difficulties.

Furthermore, the inclusion of self-identified autistic individuals provides the advantage of capturing a broader spectrum of experiences, particularly those who may face barriers to formal diagnosis. However, it also introduces potential variability in self-identification, which could affect the generalisability of the findings. The study aimed to minimise this by capturing scores on the RAADS-14 measure. All participants scored within the expected range of scores for autistic adults, suggesting that they would be likely to meet the clinical threshold for formal diagnosis.

Lastly, the use of a consultation group was intended to reduce neurotypical bias in the design of the study and interpretation of findings, given that the research was conducted by a non-autistic researcher. It may have been useful to send individual summaries back to participants to check if the codes/ key themes generated fit with the meaning they had intended. Whilst consultation may have helped with reducing neurotypical assumptions, it would not be possible to identify which each individual's unique experience, and so this may have been a valuable extra step to ensuring that autistic participants voices were represented authentically.

Implications

Environmental Intervention

There are several implications for practice arising from these findings. Many of the participants in the current study and autistic adults in prior research are clearly expressing that the existing therapeutic support is not adequate for supporting their mental health. Given what is known about the unique challenges of internalised ableism faced by autistic people, it may be hypothesised that the perception of

therapy as unhelpful is because autistic people are accessing individual- level interventions which are, by design, about making personal changes to better adapt to circumstances. Meanwhile, the social disability model of autism suggests that change needs to occur at the environmental and societal level. If the goal is to increase autistic adults' self-acceptance, it is therefore imperative to consider not only individual-level interventions, but also consider wider systemic interventions, such as increasing awareness of neurodiversity, revising policies of work and education institutions to routinely accommodate autistic pupils and employees, and training for organisations and staff (ideally led by autistic people themselves, such as through collaboration with advocacy groups). The participants in this study clearly identified their ability to thrive when the appropriate accommodations were put into place.

Mental Health Support

In recognition that changes to the environment are a wider societal issue that is likely to take time and sustained efforts, it would be useful to consider what support can be given to autistic individuals in the present. In this study, autistic adults outlined a number of strategies and supports that they found useful for improving autistic mental health.

It should be noted that not all participants had found therapy unhelpful. Those that benefitted from therapy highlighted that trust, validation, and a shared understanding of neurodiversity were key elements. These qualities may have contributed to self-acceptance by allowing participants to reduce self-blame and feel more aligned with the self. (Klussman et al., 2022). Therefore, this is not to suggest that autistic adults should not be offered individual psychotherapy if they desire; in

fact, a recent systematic review of randomised controlled trials recommends autistic people are “given access to mental health interventions available to non-autistic people, following principles of person-centred care” (Lindon et al., 2022). Withholding access to therapeutic interventions may also be experienced negatively as another instance of being rejected or excluded from services due to neurodiversity, as highlighted by participants in this study.

The study offers several recommendations for therapeutic practice. It would be beneficial to move away from setting therapy goals centred on achieving neurotypical behaviours. Instead, therapy should focus on understanding and supporting the individual’s sense of self within the context of neurodiversity and other significant aspects of identity. Emphasising validation and fostering self-acceptance can more effectively facilitate meaningful personal development and well-being.

For individuals seeking specific strategies, it may be useful to draw on the self-management strategies that the evidence-base has identified autistic people find helpful. This study highlighted adopting healthy lifestyle habits, social selectivity, reducing demands, self-help mood strategies, routines, planning, and engagement in special interests as beneficial towards improving autistic mental health.

The way in which anxiety, depression, and related emotional difficulties are measured in this group may differ from other populations. Participants expressed a preference for focusing on emotion management rather than simply reducing symptoms, which is often the primary goal of traditional talking therapy services. They may benefit from outcome measures that concentrate on concepts such as emotional regulation or self-acceptance. Given the consensus that therapy was more effective when it was person-centred and informed by neurodiversity, participants

might prefer goal-based outcomes developed collaboratively with them and assessed in ways that align with their individual context. Consideration should also be given to alternatives or adjuncts to therapy. Participants in the current sample identified a broad range of alternative forms of support such as tutors, advocacy groups, coaching, financial support, community services, and medication. This again illustrates how the wider environment contributes to autistic mental health – helpful community services and financial support are made more readily available when there is an increased understanding of autistic needs. However, consideration of other avenues such as advocacy, support groups, and coaching with other autistic individuals may all help to foster safe spaces where autistic people can connect with others who give them a sense of shared understanding, belonging, and validation. These findings strongly support existing literature by Chapman and Botha (2022) on neurodiversity-informed therapy. In their paper, emphasis is placed on the need for therapists to “cultivate a relational epistemic humility regarding different experiences of neurodiversity and disablement.”

Future Research

This study highlighted a number of important implications for autistic mental health. Future research can build on the present findings by exploring the efficacy of neuro-affirmative individual therapies as well as environmental-level interventions such as teaching or training in organisations and policy-level change as opposed to individual-level therapy. Such interventions should focus on reducing the pressure to conform for autistic individuals as indicated by the research. Consideration should also be given to exploring the psychological outcomes of providing alternative forms of support to therapy such as those outlined (e.g. advocacy groups, volunteering, healthy lifestyle changes, financial support, etc.)

This research aimed to explore autistic mental health within a diverse autistic sample. Future research could continue to explore the intersectional experiences of mental health improvements and/ or recovery among autistic adults with co-occurring learning disabilities, a population excluded from the present study, as well as other commonly co-occurring types of neurodiversity, such as ADHD and dyspraxia. Addressing this gap can build on knowledge of how mental health interventions can be tailored to meet the needs of individuals with autism. By integrating these research directions, future studies can contribute to a more comprehensive understanding of mental health in autistic adults and inform the development of holistic support strategies.

Conclusion

The findings highlight the complexity of autistic mental health, revealing significant influences from personal factors, interpersonal dynamics, and environmental factors. Central to these findings is the recognition that many participants perceive their mental health journey as one of ongoing management rather than complete recovery, aligning with contemporary neurodiversity paradigms. Self-acceptance emerged as an important facilitator of wellbeing, achieved by understanding oneself through accessible autism resources and challenging internalised ableism.

Participants also highlighted the key role of interpersonal acceptance and environmental accommodations in fostering wellbeing. These findings lend support to advocacy for wider systemic changes in educational and workplace settings to better support autistic individuals, emphasising the importance of accommodations and awareness of neurodiversity. Additionally, the intersectionality of identity,

including factors such as age, gender, ethnicity, and culture, was found to intersect with mental health experiences, emphasising the need for inclusivity in both research and mental health support.

The implications for practice suggest that therapeutic interventions should prioritise validating approaches aimed at enhancing self-acceptance, rather than aiming to conform autistic individuals to neurotypical standards. Furthermore, the study advocates for the provision of support beyond therapy, such as support groups, coaching, and advocacy, which provide crucial spaces for affinity and validation amongst autistic peers.

In conclusion, this study contributes valuable insights into the nuanced experiences of autistic adults regarding mental health improvements. By advocating for systemic changes and embracing neurodiversity, holistic mental health support can be provided for autistic adults.

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Part 3:

Critical Appraisal

Completing this research project has felt significant and meaningful in a number of ways. In this critical appraisal, I intend to explore reflections on some of the decisions I made during the research process as well as reflections on the value of the research.

My Role as a Non-Autistic Researcher

I was particularly conscious of my role in this project as a non-autistic researcher. As a Trainee Clinical Psychologist, it is in line with my values to work in a person-centred way and minimise emotional harm. For this reason, I felt an overwhelming responsibility to ensure that the write-up of my project was of benefit

to autistic mental health and would not cause unintentional harm, either directly to the participants or indirectly to the autistic community through the content of the research findings. This factored into a number of my decisions, particularly my decision to undertake a qualitative research approach for my empirical study, using reflexive thematic analysis, as it allowed me to platform the voices of the autistic adults and highlight key themes arising from their own views rather than mine. I am aware of the wider context around autistic mental health research and that there is a lack of lived experience qualitative research that highlights the voices of autistic participants directly, with an oversaturation of quantitative paediatric research. I am also aware that autistic people would like more mental health research as outlined as a key priority (NHS Long Term Plan, 2019). It was clear to me that this would be a meaningful and valued topic that had the potential to add important knowledge to the evidence base. On the other hand, I am aware that the Reflexive Thematic Analysis (Braun & Clarke, 2021) approach acknowledges that the researcher's views inevitably influence the research process. I had to acknowledge that as a non-autistic researcher, this could be a dilemma when undertaking this project. As such, plenty of thought went into ensuring that the topic was approached sensitively and carefully to avoid furthering unhelpful or outdated ideologies. This was of significant importance to me and formed the basis of many of my reflective notes throughout the process. This section will explore some personal reflections on the process of completing a research project on autistic adults' mental health as a non-autistic researcher.

Prior Knowledge of Autism

As a Trainee Clinical Psychologist, I have worked in autism services and had the pleasure of working with many autistic people and their families. Throughout my clinical practice I have become aware of a number of the challenges experienced by

the autistic community. From working in and alongside neurodevelopmental teams, I am aware of the stigma and lack of understanding that has historically surrounded autism diagnosis. However, as a young professional, I have also had the benefit of witnessing the more recent paradigm shift that embraces neurodiversity and rejects the deficit model of autism. I have found that this is not reflected in much of the literature, with plenty of the research continuing to focus on quantitative outcome measures based on 'symptoms' or 'deficits' of autism. It was therefore crucial to me that if I were to produce autism research that were meaningful and beneficial for autistic people, I must adopt a neuroaffirmative approach to the way I interpret and report any of the findings.

Literature Review

I arrived at my literature review topic on loss of autism diagnosis by scoping the existing autism literature and through multiple discussions with my supervisor on current topics in the field. I came across the term "optimal outcomes" which is used in many of the studies. With a mental health focus in mind, likely due to my background in Clinical Psychology, I had expected "optimal outcomes" to refer to wellbeing outcomes such as quality of life, low levels of anxiety, high self-esteem, etc. Instead, I quickly realised that this term had been attributed to individuals who were perceived to have 'lost' their diagnosis of autism by overcoming their autistic traits. In itself, that appears problematic, as it assumes that it is optimum to be neurotypical. This was clearly not in line with the neurodiversity approach that I have seen embraced by the autistic community. I was therefore interested in exploring this further. I made the decision to distance from the term "optimal outcomes" when writing up the report, instead referring to it more neutrally as "loss of autism diagnosis". I am aware that there would be benefit in using the term "optimal

outcomes" to match what is frequently used in the prior evidence-base. However, ethically, it felt more important to me to adopt language that was neuroaffirmative in nature and to make my stance clear and transparent. I felt a responsibility to reject outdated and unhelpful narratives.

I did feel some hesitation about pursuing this topic. I am aware that the "optimal outcomes" literature can be considered controversial, and I was keen not to add to controversy by producing research that furthers the stigma towards autism. It was my first time completing a systematic literature review, and I thought about how the findings would largely depend on kind of research had been published before me. I was mindful that much of the research has been conducted within a deficit-model of autism and therefore considered the possibility that the findings of the systematic literature review may be unfavourable in some way, such as suggesting that autistic people could "overcome" autism or would be too highlighting of deficits. I wanted to strike the right balance of both analysing and summarising the existing evidence accurately, and remaining ethical and neuroaffirmative in the outcomes reported. By considering the evidence base against a number of hypotheses, it allowed me to highlight alternative narratives whilst remaining balanced in my narrative synthesis of the literature. Ultimately, the research findings did support a neurodiversity approach to autism and therefore this was not an ethical dilemma that I had to resolve when it came to reporting my findings. However, it does raise some interesting reflections on the personal and professional dilemma for researchers to report unbiased, objective research findings whilst also recognising the ethical responsibility to consider the implications of such research and ensuring it does not cause harm to the research population it is based on.

Empirical Paper

Accessibility

One of my primary concerns was ensuring that study participation was accessible. I thought carefully with my supervisor and the consultation working group in the design stages about how to ensure this was the case. I attempted to think about the research through the lens of the participant journey, imagining how the study may be experienced from start to finish. This informed my decision on how the research interviews would be conducted; maximum flexibility in the format including face to face, video call, telephone, or chat-based interviews. My intention was to recognise that different autistic people would have different social and communication needs, and that by offering a range of flexible communication methods they could choose the approach that best suited their needs. I found that the majority opted for video call interviews but there were also some telephone and face to face interviews. This preference for online participation may reflect the fact that my recruitment took place largely online.

In hindsight, I would have liked to have increased accessibility by ensuring the study was better advertised to those who may not be online. I had sent the research poster to autism support groups and asked for it to be displayed/ distributed, but I had no confirmation of this occurring outside of the poster being shared in online newsletters.

Language Sensitivity

Another area I thought carefully about throughout the research was the language used. Having engaged in a number of reflective groups on “Social GGRRAAACCEEESSS” (Burnham, 2012), I’m particularly mindful of the fact that we each have blind spots when it comes to social characteristics that we do not identify

with. I reflected a lot throughout the research process on the blind spots I may have in relation to autism. However, I recognised that self-reflection would be limited in recognising what these blind spots may be. I thought of this in the context of the conscious competence model (Howell & Fleishman, 1982), i.e. I recognised that there is a level of 'unconscious incompetence'; despite having positive intentions, one may not always know or be able to identify where they lack knowledge or understanding. It was helpful to be able to review the study design and materials with the autistic consultation group for this purpose. There were indeed blind spots identified where I had unintentionally used language that may be perceived negatively by autistic people. For example, I had used the phrase "social difficulties" to describe autistic participants experiences when I was actually referring to the social mismatch that occurred between autistic and neurotypical people. Without meaning to, I had adopted language typical of the deficit-model of autism. Another example is where I had labelled a theme "behavioural change" referring to the helpful self-management strategies adopted by autistic participants but had failed to recognise the negative association this has with controversial behavioural approaches such as Applied Behaviour Analysis (ABA), and how this therefore may be misperceived. I found it incredibly helpful to have this additional perspective to highlight my blind spots and ensure that the research findings were reported in a way that was considerate and respectful of neurodivergence.

It prompted me to think about the best practice for autism research. There has been a rise in coproduction and involvement of experts by experience, and I personally felt as though my research project really highlighted the value of this. From following various autistic advocates on social media and online spaces, I am aware that many autistic people would like research conducted by or with autistic

people. I am glad I did engage with autistic adults when designing and interpreting my research, as it offered meaningful insight to my project. For this reason, I believe it should be standard practice to at minimum consult with autistic individuals in autism-related research, with the ideal being to co-produce such research. I was limited in my capacity for consultation meetings as I wanted to ensure my autistic consultants were compensated appropriately for their time and had to factor in my research budget. If this was not a limiting factor, I may have also wanted to involve autistic researchers in more stages of the project, such as during coding or generating initial themes.

Capturing Diverse Experiences

When recruiting, I had a much greater number of autistic adults expressing interest to take part in the study than there were participant spaces. Although this meant I was unfortunately unable to involve all of the participants who had hoped to contribute their experiences to the study, it did offer me a larger pool of participants to recruit from, so that I could try to recruit a diverse sample. I made the decision to use stratified sampling based on age, gender and ethnicity, in recognition that much of the existing autism research is over reliant on white, paediatric male populations. It was important to me that, just as I was aiming to authentically represent the autistic voice in my research, I ensured that this reflected autistic people through an intersectional lens, so that all perspectives were represented. By doing so, I aimed to capture a wide array of experiences and ensure that the research findings were representative of the broader autistic community. I paid particular attention to including voices that are often marginalised or underrepresented in research, such as those of autistic women, non-binary individuals, and ethnic minorities.

In hindsight, I have reflected on the impact of not including socioeconomic status in my stratified sampling approach. I believe it would have been helpful to have ensured a mixture of socioeconomic status across the sample, or at least to have collected this information from my participants in order to characterise the sample. I think this is a limitation of the study, as I do wonder whether socioeconomic status could play a role in how improvement in autistic mental health is experienced, for example through access (or lack of) to resources such as private therapy or other paid support avenues. One participant noted financial support as a key factor in their mental health, and this also arose in discussion with an expert by experience.

The Value of Autism Research

Completing this research has been valuable in several ways. Firstly, it has contributed to the growing literature base on autistic adults' mental health, an area that is under-researched. By highlighting the lived experiences and mental health challenges experienced by autistic adults, the findings can better inform clinical practices and support services that are tailored to their needs.

Academic

The academic value of this research lies in its potential to fill significant gaps in the existing literature. Mental health issues among autistic adults are often overshadowed by a deficit-model focus on autism in childhood, leading to a lack of research on adult experiences. By shedding light on the unique mental health challenges faced by autistic adults, this study provides valuable insights that can guide future research and inform the development of targeted interventions or alternative mental health support.

Additionally, the use of reflexive thematic analysis offers a nuanced understanding of the participant experiences. This methodological approach allowed for the identification of key themes and patterns, providing a rich and detailed account of the factors that influence mental health among autistic adults. The findings from this research can serve as a foundation for further studies, helping to build a more comprehensive and inclusive body of knowledge on autism and mental health. I hope that it will encourage further research exploring intersectionality.

Lastly, when reporting my research, I highlighted the importance of involving autistic individuals in the research process and respecting their perspectives. This can serve as a basis for future studies, encouraging researchers to adopt more inclusive and participatory approaches. By promoting greater collaboration between researchers and the autistic community, this research can contribute to a more respectful, collaborative, and empowering approach to autism research.

Clinical

The practical implications of this research are equally significant. By highlighting the specific mental health needs of autistic adults, the study provides valuable information that can inform clinical practice and service provision. Mental health professionals can use these insights to develop more effective and personalised support, ensuring that autistic adults receive the care they need to thrive. For instance, the research findings reveal common stressors and triggers that exacerbate mental health issues amongst autistic adults. With this knowledge, clinicians can work with their clients to develop coping strategies and interventions that address these specific challenges. Additionally, the study's emphasis on neuroaffirmative approaches and the provision of accommodations can guide the

design of mental health and wider services, ensuring that they are more attuned to the needs of autistic individuals.

Advocacy and Policy

Beyond the immediate practical applications, this research has the potential to inform broader advocacy and policy efforts. By providing empirical evidence of the mental health challenges faced by autistic adults, the study can help to raise awareness and drive change at the policy level. Advocacy groups can use these findings to campaign for better mental health services, increased funding for autism research, and greater recognition of the unique needs of autistic adults.

Personal and Professional Development

On a personal level, completing this research has deepened my understanding and empathy towards the autistic community. By engaging with the autistic participants and listening to their voices, I have gained a deeper appreciation for the diversity and complexity of autistic experiences. It has strengthened my commitment to advocating for the rights of neurodiverse individuals and their well-being as a future clinical psychologist. This will inform my future work as a clinician when working with neurodiverse individuals. In particular, the emphasis on accessibility and inclusivity will inform my approach to clinical practice. I will aim to create a supportive and accommodating environment for my clients, recognising the importance of flexibility and individualised care. By incorporating the principles of inclusive practice into my work, I hope to contribute to a more helpful and supportive mental health system.

The research journey has also been a learning experience. It has challenged me to critically examine my assumptions and biases, fostering a greater sense of

self-awareness and reflexivity. By remaining open to new perspectives and willing to learn from the participants, I have been able to approach the research with greater humility and sensitivity.

Conclusion

To conclude, I have approached this project as a non-autistic researcher with a commitment to reflexivity, sensitivity, and humility. The process has been challenging at times, particularly due to the personal responsibility I felt to produce neuroaffirmative research that is of benefit to the autistic community. This has required careful consideration of accessibility, thoughtful use of language, and continuous self-reflection to identify and address my own blind spots. Balancing the need to produce balanced, objective research findings and minimising the influence of my own views has been a critical aspect of this process.

Despite the challenges, the research has been profoundly meaningful and impactful. It has felt like a privilege to be trusted by my research participants with their stories, and I have tried my best to honour this trust by portraying their experiences as authentically as possible.

Through this project, I have gained valuable insights into identifying areas of improvement in the academic, clinical, policy, and personal dimensions of autistic adults' mental health, which has emphasised how impactful research can be. Academically, this research contributes to a growing body of knowledge on autistic adults' mental health, addressing an often under researched area. Clinically, the findings provide valuable information that can inform more effective and personalised mental health support provided to autistic individuals. From a policy perspective, the research highlights the need for improved mental health services and increased

recognition of the unique needs of autistic adults in wider society. Personally, the process has deepened my empathy and understanding of the autism community and will benefit my clinical practice when working with neurodiversity.

By amplifying the voices of autistic adults and highlighting their mental health needs, I hope this study contributes to a more inclusive and supportive society and mental healthcare system.

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Appendices

Appendix A: Table 2 - Studies Included in Literature Review

***** *= Studies that included participants from Fein et al (2013)*

	DOI	Year	Full Citation	Participants overview	Key Outcomes
1	N/A – Thesis	2009	Berry, L. N. (2009). Early treatments associated with optimal outcome in children with autism spectrum disorders (Order No. 3377035). Available from ProQuest Dissertations & Theses Global. (304872153). Retrieved from https://www.proquest.com/dissertations-theses/early-treatments-associated-with-optimal-outcome/docview/304872153/se-2	ASD-NON (N=12) ASD-ASD (n=102) Ages 16mo – 30mo 83%M, 17%F 91.7% Caucasian	-In total, 6.8% diagnosed with Autistic Disorder moved off the spectrum -Strong trend towards higher IQ in LAD group -No statistically significant findings between LAD and TD in a number of areas -Many individuals who lost autism diagnosis gained another neurodevelopmental diagnosis.

2	10.1177/1362361315607724	2016	Blumberg, S. J., Zablotsky, B., Avila, R. M., Colpe, L. J., Pringle, B. A., & Kogan, M. D. (2016). Diagnosis lost: Differences between children who had and who currently have an autism spectrum disorder diagnosis. Autism, 20(7), 783–795. doi:10.1177/1362361315607724	Current ASD (n= 1420) Previously diagnosed ASD (n=187) Age 6-11yrs (62%) 12-17 (37.9%) 74%M, 26%F 54% Caucasian 10% Black 10% Hispanic 26% Other	-13% lost the Autism diagnosis. - Differences in clinical characteristics, mainly functioning of the child. -Children with a previous diagnosis more likely to currently possess daily living skills. -Children previously diagnosed less likely to have been referred to a specialist -Previously diagnosed less likely to have received a subtype with diagnosis
3	10.1044/2015_jslhr-l-15-0022	2016	Canfield, A. R., Eigsti, I.-M., de Marchena, A., & Fein, D. (2016). Story goodness in adolescents with autism spectrum disorder (ASD) and in optimal outcomes from ASD. Journal of Speech, Language, and Hearing Research, 59(3), 533–545. https://doi.org/10.1044/2015_jslhr-l-15-0022	OO = 15, HFA = 14, TD = 15 Mean age 13yrs 80%F, 20%M Ethnicity not reported	-No group differences between the HFA, OO, and TD groups on the measures of story grammar, mental state language, added/invented details, or narrative length. -The OO and TD groups differed on ratings of goodness and cohesiveness. Although individuals with OO are virtually indistinguishable from their peers with TD in many ways, they show continued subtle difficulty in pragmatic language. -Results indicate subtle differences in pragmatic language skills for individuals with optimal outcomes despite otherwise typical language skills in other domains.

4	10.3389/fpsyt.2023.1105253	2023	Colombi C, Chericoni N, Bargagna S, Costanzo V, Devescovi R, Lecciso F, Pierotti C, Prosperi M and Contaldo A (2023) Case report: Preemptive intervention for an infant with early signs of autism spectrum disorder during the first year of life. Front. Psychiatry 14:1105253.	1 male (case study) Throughout infancy White Italian	Based on these measures and clinical judgment, Francesco showed a significant improvement in developmental skills and did not meet criteria for a diagnosis of ASD when formally evaluated at 32 months of age.
5*	10.1016/j.rasd.2023.102252	2023	Crutcher, J., Butler, E., Burke, J. D., Naigles, L., Fein, D. A., & Eigsti, I.-M. (2023). Pragmatic language and associations with externalizing behaviors in autistic individuals and those who have lost the autism diagnosis. *Research in Autism Spectrum Disorders*, *108*, 102252. https://doi.org/10.1016/j.rasd.2023.102252	LAD (n=31) ASD (n=33) TD (n=34) 24M, 31F 92% Caucasian	-ASD group had sig lower pragmatic lang than LAD/NT groups. No difference between LAD and NT. ASD group had sig more ADHD symptoms than LAD/NT. No difference in groups in ODD/CD (low for all) . Participants in the ASD group had cognitive abilities in the average range, but still struggled with pragmatic language. This group had lower scores on both verbal IQ and structural language measures; weaknesses in pragmatic language remained even when scores on the former measures were included as covariates. LAD higher autism than NT

6	10.1186/s13052-021-01008-5	2021	Di Renzo, M., di Castelbianco, F. B., Alberto, V., Antonio, D. V., Giovanni, C., Vanadia, E., Petrillo, M., Davide, T., Racinaro, L., & Rea, M. (2021). Prognostic factors and predictors of outcome in children with autism spectrum disorder: the role of the paediatrician. Italian journal of pediatrics, 47(1), 67. https://doi.org/10.1186/s13052-021-01008-5	40 children (ASD-ASD = 25) (ASD-OO = 15) Avg 3yrs (ASD = 82%M, 18%F OO= 72%M, 28%F) Based in Italy Ethnicities not known	15 out of 40 children, after at least for 2 years no longer fell into the diagnostic ASD category The children in the ASD-OO group initially had a higher IQ than those in the ASD-ASD group, lower severity of autistic symptoms, greater understanding of intentions, more emotional contagion, and better quality of play. The results suggest that the initial coexistence of skills in these areas at the time of the first diagnostic assessment may allow us to predict the possibility of achieving optimal outcome after 2 years of therapy.
7*	10.1002/aur.1324	2013	Eigsti, I., & Fein, D. A. (2013). More is less: Pitch discrimination and language delays in children with optimal outcomes from autism. Autism Research, 6(6), 605–613. doi:10.1002/aur.1324	26 teenagers with optimal outcomes, 29 teenagers with high-functioning autism, and 20 teenagers with typical development. (total n = 75) Age 8-21 (Mean age 12) 20M, 6F Ethnicity not reported	-ASD group showed the best pitch discrimination, followed by the OO group, then TD group. -Symptom severity accounted for unique and significant variance in individual differences in pitch perception abilities, even controlling for age and IQ. -OO group showed a tendency to produce first words later, on average, than the ASD group at 27.2 months versus 21.0 months, respectively, though first phrases were produced at a similar time, at 35.2 months versus 35.4 months. This further strengthens the argument that participants in the OO group had similar symptom severity early in development.

8*	doi:10.1016/j.nicl.2015.11.014	2016	Eigsti, I.-M., Stevens, M. C., Schultz, R. T., Barton, M., Kelley, E., Naigles, L., … Fein, D. A. (2016). Language comprehension and brain function in individuals with an optimal outcome from autism. *NeuroImage: Clinical*, *10*, 182–191. doi:10.1016/j.nicl.2015.11.014	High-functioning ASD (n=23),OO(n=16), or typical development (TD; n=20) Individuals ages 8 to 21 years 15M, 1F Ethnicity not reported	-Results indicated similar activations in frontal and temporal regions (left middle frontal, left supramarginal, and right superior temporal gyri) and posterior cingulate in OO and ASD groups, where both differed from the TD group. -OO group showed heightened “compensatory” activation in numerous left- and right-lateralized regions (left precentral/postcentral gyri, right precentral gyrus, left inferior parietal lobule, right supramarginal gyrus, left superior temporal/ parahippocampal gyrus, left middle occipital gyrus) and cerebellum, relative to both ASD and TD groups. - Behaviourally normalized language abilities in OO individuals appear to utilize atypical brain networks, with increased recruitment of language-specific as well as right homologue and other systems. Early intensive learning and experience may normalize behavioural language performance in OO, but some brain regions involved in language processing may continue to display characteristics that are more similar to ASD than TD, while others show characteristics not like ASD or typical development.

9	https://dx.doi.org/10.1111/jcpp.13551	2022	Elias, R., & Lord, C. (2021). Diagnostic stability in individuals with autism spectrum disorder: Insights from a longitudinal follow-up study. Journal of Child Psychology and Psychiatry, 63(9), 973–983. doi:10.1111/jcpp.13551	155 (LAD=13) Age 2-25 (longitudinal) Approx 80%M, 20%F 92% Caucasian, 8% Black	A subset of participants was assigned a diagnosis in adulthood that differed from diagnoses earlier in development. Across cog levels, the majority of novel diagnoses emerged in adulthood. Improvements in ADOS CSS over time for the Lost Diagnosis group and worsening in CSS in the Gained Diagnosis group were gradual. Individuals who lost a diagnosis even in adulthood could be distinguished on CSS and ADI-R scores by age 5 from those who retained their ASD diagnosis. Although most participants with VIQ < 70 saw decreases in autistic symptoms as a whole, changes in autism diagnoses were confounded by disentangling profound intellectual disability as a differential diagnosis or co-occurrence. Only the Never Had Diagnosis group revealed significant changes in ADOS scores over time, with autism symptoms increasing.

10*	doi:10.1111/jcpp.12037	2013	Fein, D., Barton, M., Eigsti, I., Kelley, E., Naigles, L., Schultz, R. T., … Tyson, K. (2013). Optimal outcome in individuals with a history of autism. Journal of Child Psychology and Psychiatry, 54(2), 195–205. doi:10.1111/jcpp.12037	Thirty-four individuals with a history of ASD and OO, 44 high-functioning individuals with a current ASD diagnosis (HFA), and 34 typically developing peers (TD) were tested. Participants ranged from 8 years, 1 month to 21 years, 8 months. The groups were matched on age, gender, and nonverbal IQ. OO: 27 M, 7F Participants were predominantly Caucasian, with 3 OO individuals, 2 HFA individuals, and 3 TD individuals reporting other races or ethnicities.	OO and TD groups' mean scores did not differ on socialization, communication, face recognition, or most language subscales, although three OO individuals showed below-average scores on face recognition. Early in their development, the OO group displayed milder symptoms than the HFA group in the social domain but had equally severe difficulties with communication and repetitive behaviours. VAB: Adaptive behavior did not differ in any of the three domains between the TD and OO groups. Socialization scores were virtually identical in OO and TD groups and Communication was slightly (non-significantly) higher in the OO group. Adaptive functioning was mildly delayed for the HFA group, and significantly below the other groups. Facial recognition: OO and TD same, differ from HFA.

11*	https://dx.doi.org/10.1007/s10803-014-2347-8	2015	Fitch, A., Fein, D. A., & Eigsti, I.-M. (2015). Detail and gestalt focus in individuals with optimal outcomes from Autism Spectrum Disorders. Journal of Autism and Developmental Disorders, 45(6), 1887–1896. doi:10.1007/s10803-014-2347-8	Fifty-nine adolescents included those with high-functioning ASD (HFA; n = 20), a history of typical development (TD; n = 17), or with optimal outcomes from ASD (OO;22) Mean age 13yrs Gender & ethnicity not known	-Participants in global/local focus, whereas both groups (TD, OO) differed from the HFA group. -This result is consistent with two possibilities: First, the OO group may never have shown the global/local focus that characterized the HFA group's performance. Their typical processing style may have been present throughout development, including the period when they had active symptoms of ASD. A second possibility is that participants with OO had a global/local focus similar to the HFA group early in development, but that this focus has changed over time, potentially in tandem with the loss.
12	https://doi.org/10.1007/s10803-019-03935-z	2019	Hrdlicka, M., Kudr, M., Krsek, P., Tichy, M., Kyncl, M., Zamecnik, J., … Dudova, I. (2019). Recovery from autism after successful surgery for a benign brain tumor associated with epilepsy. Journal of Autism and Developmental Disorders, 49(12), 5100–5104. doi:10.1007/s10803-019-03935-z	n = 1 (case study) Male Age 3yrs Ethnicity not reported	Child fell below diagnostic threshold after having surgery for brain tumour

13*	https://dx.doi.org/10.1007/s10803-015-2651-y	2015	Irvine, C. A., Eigsti, I.-M., & Fein, D. A. (2015). Uh, UM, and autism: Filler disfluencies as pragmatic markers in adolescents with optimal outcomes from autism spectrum disorder. Journal of Autism and Developmental Disorders, 46(3), 1061–1070. doi:10.1007/s10803-015-2651-y	Participants included individuals between 8 and 21 years with a history of ASD who achieved optimal outcomes (OO; n = 24); high-functioning individuals with a current ASD diagnosis (ASD; n = 24); and individuals with a history of typical development (TD; n = 16). Avg 13.6yrs 19M, 5F Ethnicity not reported	While uh rates did not differ, participants with ASD produced um less frequently than OO or TD groups. Um rate was associated with autism symptom severity, but not executive function or language abilities, suggesting that um serves a pragmatic, listener-oriented function. Moreover, in contrast to minimal production in ASD, the typical OO um production substantiates the normalization of subtle social communication in this population.
14*	https://doi.org/10.1038/s41598-020-72896-6	2020	Jaffe-Dax, S., & Eigsti, I.-M. (2020). Perceptual inference is impaired in individuals with ASD and intact in individuals who have lost the autism diagnosis. Scientific Reports, 10(1). doi:10.1038/s41598-020-72896-6	Individuals with LAD (n = 27), ASD (n = 29), and TD (n = 23) Mean age 12.5. Participants ranged in age from 8 to 21 years. 21M, 6F Ethnicity not reported	This study looked at how people with ASD and those who used to have ASD but don't anymore (LAD) perceive sounds. It found that people with ASD tend to perceive sounds differently from others, but those who used to have ASD but don't anymore perceive sounds more like people without ASD. This tells us that changes in how people with ASD perceive things might be linked to their symptoms, and understanding these changes could help us better understand and support people with ASD.

15	doi:10.1016/j.rasd.2009.12.001	2010	Kelley, E., Naigles, L., & Fein, D. (2010). An in-depth examination of optimal outcome children with a history of autism spectrum disorders. Research in Autism Spectrum Disorders, 4(3), 526–538. doi:10.1016/j.rasd.2009.12.001	13 children with a history of ASD who had reached an optimal outcome level (the OO group), 14 typically developing children (the TD group), and 14 children on the autism spectrum who were of average intelligence Mean 10 years, 5 months 10 boys, 3 girls Ethnicity not reported	Unlike their high-functioning peers with ASD, the OO group's adaptive and problem behavior scores fell within the average range. They also showed average language and communication scores on all language measures. The HFA group, however, continued to show pragmatic, linguistic, social, and behavioural difficulties. The OO children tended to have been diagnosed at younger ages and were significantly more likely to have received intensive early intervention. Although the high functioning children with ASD continued to show difficulties in the behavioural realm, the individuals in the OO group were functioning within the average range on all measures.
16	https://dx.doi.org/10.1007/s10803-006-0111-4	2006	Kelley, E., Paul, J. J., Fein, D., & Naigles, L. R. (2006). Residual language deficits in optimal outcome children with a history of autism. *Journal of Autism and Developmental Disorders*, *36*(6), 807–828. doi:10.1007/s10803-006-0111-4	n = 28 age 5 to nine, mean 78.71 months (6.56 years) 12M, 2F Ethnicity not reported	Results indicated that while these children's grammatical capabilities are mostly indistinguishable from their peers, they are still experiencing difficulties in pragmatic and semantic language.

17	https://doi.org/10.1007/s10803-019-04138-2	2019	Giserman-Kiss, I., & Carter, A. S. (2019). Stability of autism spectrum disorder in young children with diverse backgrounds. *Journal of Autism and Developmental Disorders*, *50*(9), 3263–3275. doi:10.1007/s10803-019-04138-2	n = 61 Children ranged in age from 42 to 70 months (mean = 51.3 months; SD = 7.0 months) at follow-up evaluations. 87% male, 13% female Participants and families were diverse with regard to race/ethnicity (79.7% identified as racial/ethnic minorities).	Follow-up evaluations determined that seven children (11.7% of sample) no longer met DSM-5 diagnostic criteria for ASD. children demonstrated significantly improved cognitive abilities (including nonverbal problem-solving, fine motor, receptive language, and expressive language skills) as well as significantly decreased ASD symptom severity at follow-up. No difference between different ethnicities
18*	doi:10.1016/j.nicl.2022.103043	2022	Larson, C., Rivera-Figueroa, K., Thomas, H. R., Fein, D., Stevens, M. C., & Eigsti, I.-M. (2022). Structural language impairment in autism spectrum disorder versus loss of autism diagnosis: Behavioral and neural characteristics. *NeuroImage: Clinical*, *34*, 103043. doi:10.1016/j.nicl.2022.103043	The study involved three groups: ASD (35 people), LAD (31 people), and Neurotypical (34 people). Mean age 12.97yrs LAD: 4 female, 3 male, no ASD females, only 8 ASD males Ethnicity not reported	A similar proportion of ASD (22.9%) and LAD (22.6%) participants met clinical marker criterion (i.e., ≤7 scaled score for Recalling Sentences) for structural language impairment. Additionally, the ASD-LI and LAD-LI groups differed from the NT group on all language measures, Social Communication Questionnaire scores (i.e., social communication-repetitive behavior), and ADHD status, but not nonverbal ability. Taken together, these results suggest that structural language impairment presents similarly in ASD and LAD, even in the absence of current ASD diagnostic features in LAD. This finding aligns with prior work demonstrating subtle, yet inconsistent deficits in language in LAD relative to NT peers

19	https://dx.doi.org/10.1155/2014/472120	2014	Mukaddes, N. M., Tutkunkardas, M. D., Sari, O., Aydin, A., & Kozanoglu, P. (2014). Characteristics of children who lost the diagnosis of autism: A sample from Istanbul, Turkey. Autism Research and Treatment, 2014, 1–10. doi:10.1155/2014/472120	39 (30 male 9 female) The mean age at referral was 2.39±0.75years Ethnicity not reported	It could be concluded that a group of children with an autism diagnosis could lose the diagnosis of autism upon early intervention. High IQ and the development of communicative and language skills at an early age could be the most powerful factors contributing to an optimal outcome. The mean age at referral was 2.39 ± 0.75 years (range: 1.5–4.5 years), which was also the age to start special education. The children started to talk with meaningful words at the age of 2.46 ± 0.92 years (range: 1.5–4.5 years) and used phrases at the age of 3.20 ± 0.91 years (range: 2–5 years). The mean age at optimal outcome was 5.11 ± 1.95 years. The mean number of psychiatric interviews from intake to the time of optimal outcome was 8.47 ± 3.89 sessions. Some patients are being followed up for other psychiatric problems after loss of ASD diagnosis.

20*	https://dx.doi.org/10.1007/s10803-015-2520-8	2015a	Orinstein, A., Tyson, K. E., Suh, J., Troyb, E., Helt, M., Rosenthal, M., … Fein, D. A. (2015). Psychiatric symptoms in youth with a history of autism and optimal outcome. *Journal of Autism and Developmental Disorders*, *45*(11), 3703–3714. doi:10.1007/s10803-015-2520-8	33 OO, 42 high-functioning autism (HFA) and 34 typically developing (TD) youth Age 8-21 TD (31m 3f) , OO (26m 7f), HFA (38m 4f) Participants were mostly Caucasian, with 3 OO and 2 HFA individuals reporting other races or ethnicities.	OO and HFA groups had elevated current ADHD and specific phobias, with tics in HFA. In the past, the HFA group also had elevated depression and ODD, and the OO group had tics. The HFA group also showed subthreshold symptoms of specific and social phobias, and generalized anxiety. Psychopathology in the OO group abated over time as did their autism and decreased more than in HFA.

21 *	https://10.1097/DBP.0000000000000037	2014	Orinstein, A. J., Helt, M., Troyb, E., Tyson, K. E., Barton, M. L., Eigsti, I.-M., Naigles, L., & Fein, D. A. (2014). Intervention for optimal outcome in children and adolescents with a history of autism. Journal of Developmental & Behavioral Pediatrics, 35(4), 247–256. https://doi.org/10.1097/dbp.0000000000000037	-The current study examined intervention histories in 34 individuals with OO and 44 individuals with HFA. -Age 8-21yrs -Gender (HFA=31 males:3 females, OO=20:5) -Participants were mostly Caucasian, with 3 OO and 2 HFA individuals reporting other races or ethnicities. -Families were generally of middle and high income, with 13 of 30 HFA families (43%) earning under $100,000 per year, and 17 earning over $100,000. For the OO group, 10 of 24 (42%) earned under $100,000 and 14 over $100,000. Dividing up the income groups in several different ways resulted in no significant Fisher's exact test or chi-square values.	-Overall severity milder in OO group -Percentage of OO children receiving any intervention significantly higher than ASC group - Sig difference in intervention intensity between groups -More OO than ASC children received ABA -For those receiving ABA, similar intensity between groups - Children with current autism diagnosis more likely to receive medication, especially anti-psychotics and anti-depressants

22*	https://doi:10.1007/s10803-015-2409-6	2015b	Orinstein, A. J., Suh, J., Porter, K., De Yoe, K. A., Tyson, K. E., Troyb, E., … Fein, D. A. (2015). Social function and communication in Optimal Outcome Children and adolescents with an autism history on structured test measures. Journal of Autism and Developmental Disorders, 45(8), 2443–2463. doi:10.1007/s10803-015-2409-6	44 high-functioning autism (HFA), 34 optimal outcome (OO) and 34 typically developing (TD) youth. 8-21 yrs. OO (27m, 7f) Participants were predominantly Caucasian, with 3 OO individuals, 2 HFA individuals, and 3 TD individuals reporting other races or ethnicities	Results indicated that OO participants had no autism communication symptoms, no pragmatic language deficits, and were judged as likable as TD peers. Some group differences were found: OO youth had less insight into social relationships and poorer friendship descriptions than TD youth. OO participants had attention, self-control, and immaturity difficulties that may impact social abilities. However, OO participants were most engaged, friendliest, warmest, and most approachable. Overall, OO participants had no social and communicative impairments, although some exhibited mild social difficulties that often accompany attentional problems.

23	https://dx.doi.org/10.1177/088307381983442 8	2019	Shulman, L., D'Agostino, E., Lee, S., Valicenti-McDermott, M., Seijo, R., Tulloch, E., Meringolo, D., & Tarshis, N. (2019). When an early diagnosis of autism spectrum disorder resolves, what remains? Journal of Child Neurology, 34(7), 382–386. https://doi.org/10.1177/088307381983442 8	Out of 569 children, there were 38 children who were considered 'ASD residual'. 80% male, 20% female A diverse demographic representative of the community served: 36% self-identifying as Caucasian, 44% Hispanic, and 10% African American. Forty-six percent of the sample had Medicaid, and 42% were bilingual (Spanish and English). Eighty percent of the children received Early Intervention services.	Only 8% of the children warranted no diagnosis other than having had a history of ASD. Sixty-eight percent had language/ learning disabilities, 49% of the children were diagnosed with externalizing behavior problems (attention-deficit hyperactivity disorder [ADHD], oppositional defiant disorder, disruptive behavior disorder), 24% were diagnosed with internalizing problems (mood disorder, anxiety disorder, obsessive compulsive disorder [OCD], selective mutism), and 5% (n ¼ 2) were given a significant mental health diagnosis (psychotic disorder not otherwise specified). Sixty percent (n ¼ 23) of the children received 2 diagnoses, with the most common combination being language/learning disability and ADHD

24*	https://dx.doi.org/10.1007/s10803-014-2042-9	2014	Suh, J., Eigsti, I.-M., Naigles, L., Barton, M., Kelley, E., & Fein, D. (2014). Narrative performance of Optimal Outcome Children and adolescents with a history of an autism spectrum disorder (ASD). Journal of Autism and Developmental Disorders, 44(7), 1681–1694. doi:10.1007/s10803-014-2042-9	15 OO individuals, 15 high-functioning individuals with an ASD (HFA), and 15 typically developing peers (TD) OO Avg Age 12.4yrs 12M, 3F Ethnicity not reported	Despite average cognitive functioning, the ASD group produced narratives with fewer central "gist" descriptions, more ambiguous pronominal referents, idiosyncratic language, speech dysfluency (more repetitions and self-corrections), and were less likely to name story characters. The OO participants displayed only very subtle pragmatic and higher-level language deficits (idiosyncratic language and self-correction dysfluency).
25*	https://doi:10.1007/s10803-016-2868-4.	2016	Suh, J., Orinstein, A., Barton, M., Chen, C.-M., Eigsti, I.-M., Ramirez-Esparza, N., & Fein, D. (2016). Ratings of broader autism phenotype and personality traits in optimal outcomes from autism spectrum disorder. Journal of Autism and Developmental Disorders, 46(11), 3505–3518. doi:10.1007/s10803-016-2868-4	22 OO individuals, 27 high functioning individuals with ASD (HFA), and 23 typically developing (TD) peers. Age 8-18, Avg 13yrs 17M, 5F Participants were mostly Caucasian, with 3 OO and 2 HFA individuals reporting other races or ethnicities.	-Significant group differences between the OO, TD, and HFA groups for all five personality dimensions on the BFI, with the TD and OO groups different from the HFA group but not from each other on most scales. -HFA children displayed higher ratings than their peers on all BAP traits. OO were indistinguishable from TD, with the exception of greater extraversion (e.g., increased talkativeness), a potential tendency to be less emotionally stable, and pragmatic language deficits such as getting sidetracked in conversation. -Overall, OO individuals are not showing BAP characteristics, but may be subject to other mild ADHD-like characteristics.

26 *	https://dx.doi.org/10.1007/s10803-014-2182-y	2014	Troyb, E., Orinstein, A., Tyson, K., Eigsti, I.-M., Naigles, L., & Fein, D. (2014). Restricted and repetitive behaviors in individuals with a history of ASDS who have achieved optimal outcomes. Journal of Autism and Developmental Disorders, 44(12), 3168–3184. doi:10.1007/s10803-014-2182-y	34 individuals who achieved optimal outcomes (OOs; lost their ASD diagnosis), 45 high-functioning individuals with ASD (HFA) and 34 typically developing (TD) peers. Participants ranged from 8 years, 1 month to 21 years, 8 months. 27M, 7F Participants were predominantly Caucasian, with 3 OO individuals, 2 HFA individuals, and 3 TD individuals reporting other races or ethnicities.	All OO participants were reported to have at least one RRB in early childhood and almost 90% met the RRB cutoff for ASD in early childhood, but RRBs were not more present in the OO than the TD group at the time of the study. History of RRBs in the HFA and OO groups differed only in oversensitivity to noise and insistence on sameness. Reports of current behavior indicated that RRB's had almost totally disappeared in the OO group. Thus, although RRB's were present in the OO group in childhood, they resolved along with social and communication deficits. The TD and OO groups did not differ from each other on any RRB item of the ADOS. Based on parent report, the OO and TD groups only differed significantly on ritualistic behaviours, specifically rituals around eating and sleeping. Within the OO group, these RRBs did not interfere with functioning.
27 *	https://dx.doi.org/10.1177/1362361312473519	2013	Troyb, E., Orinstein, A., Tyson, K., Helt, M., Eigsti, I.-M., Stevens, M., & Fein, D. (2013). Academic abilities in children and adolescents with a history of autism spectrum disorders who have achieved optimal outcomes. Autism, 18(3), 233–243. doi:10.1177/1362361312473519	32 individuals who achieved OO, 41 high-functioning individuals with a current ASD diagnosis (HFA), and 34 typically-developing peers (TD) The participants in the study ranged from 8 years, 3 months to 21 years, 8 months. Avg 12.9 years OO 25M, 7F	All three groups performed in the average range on all subtests measured and no significant differences were found in performance of the OO and TD groups. The HFA group scored significantly lower on subtests of reading comprehension and mathematical problem solving than the OO group. These findings suggest that the academic abilities of individuals who achieved OO are similar to those of their TD peers, even in areas where individuals who have retained their ASD diagnoses exhibit some ongoing difficulty.

				Participants were predominantly Caucasian, with 3 OO individuals, 2 HFA individuals, and 3 TD individuals reporting other races or ethnicities.	
28 *	https://10.1080/09297049.2013.799644	2014	Troyb, E., Rosenthal, M., Eigsti, I.-M., Kelley, E., Tyson, K., Orinstein, A., … Fein, D. (2013). Executive functioning in individuals with a history of ASDS who have achieved optimal outcomes. Child Neuropsychology, 20(4), 378–397. doi:10.1080/09297049.2013.799644	34 individuals who achieved OOs, 43 individuals with high-functioning autism (HFA), and 34 typically-developing (TD) peers. 13.49yrs mean age OO 27M, 7F Participants were predominantly Caucasian, with 3 OO individuals, 2 HFA individuals, and 3 TD individuals reporting other races or ethnicities.	-All 3 groups demonstrated average EF; however, the OO and HFA groups exhibited more impulsivity and less efficient planning and problem-solving than the TD group + more HFA participants exhibited below average inhibition than did OO and TD participants. Parent report measures revealed average EF among the OO and TD groups; however, the OO group exhibited more difficulty than the TD group on set-shifting and working memory. HFA participants demonstrated more difficulty on all parent reported EF domains, with a clinical impairment in attention-shifting. Results suggest that EF in OO appears to be within the average range, even for functions that were impaired among individuals with HFA. Despite their average performance, however, the OO and TD groups differed on measures of impulsivity, set-shifting, problem-solving, working memory, and planning, suggesting that the OO group does not have the above-average EF scores of the TD group despite their high-average IQs.

29	https://dx.doi.org/10.1007/s10803-013-1921-9	2013	Tyson, K., Kelley, E., Fein, D., Orinstein, A., Troyb, E., Barton, M., … Rosenthal, M. (2013). Language and verbal memory in individuals with a history of autism spectrum disorders who have achieved optimal outcomes. Journal of Autism and Developmental Disorders, 44(3), 648–663. doi:10.1007/s10803-013-1921-9	44 individuals with high-functioning autism (HFA), 34 individuals with “optimal outcomes” (OO) and 34 individuals with typical development (TD). Mean age: 12.8 27M, 7F 82% Caucasian	LAD language abilities equal to TD but show greater reliance on verbal memory

Appendix B: Empirical study ethical approval

RESEARCH AND INNOVATION SERVICES

UCL

Richard Pender
Department of Clinical, Educational and Health Psychology
UCL

Cc: Rhiain Limby-Wauchope

07 August 2023

Dear Richard and Rhiain

Notification of Ethical Approval
Project ID/Title: 24669/001: Understanding autistic adults' experiences of reduction in anxiety, depression and related emotional difficulties

Thank you for submitting the above high-risk research ethics application for review by the UCL Research Ethics Committee (UCL REC).

Further to your satisfactory responses to the review feedback, I am pleased to confirm in my capacity as Chair of UCL REC that your study has been ethically approved until **31 July 2024**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
Please seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the REC any unanticipated problems or adverse events involving risks to participants or others. The REC should be notified of all serious adverse events via the Research Ethics Service (ethics@ucl.ac.uk) immediately after the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert.

For non-serious adverse events, the Joint Chairs should again be notified via the Research Ethics Service within ten days of the incident occurring and provide a full

Research Ethics Service
Research and Innovation Services
University College London
ethics@ucl.ac.uk
www.ucl.ac.uk/research-ethics/

written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the REC at the next meeting. The final view of the REC will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes issues relating to the ethical implications of the research
i.e., any issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Research Ethics Service
Research and Innovation Services
University College London
ethics@ucl.ac.uk
www.ucl.ac.uk/research-ethics/

Appendix C: Recruitment Poster

Understanding autistic adults' experiences of improvement in anxiety, depression, and related emotional difficulties

We are recruiting for interview participants!

Are you:

- **Autistic (either formally or self-identified)?**
- **Have you experienced improvement in anxiety, depression, or any other emotional difficulties?**
- **Aged between 18-65 and without a diagnosed learning disability?**

What does it involve?

- **You will be sent an information sheet containing more information about the study. If you would still like to take part, you will be invited to complete a screening survey after expressing interest.**
- **We are seeking a small representative sample. If you are selected, you will be asked some questions about your experience by a researcher in a qualitative interview.**
- **You can choose to take part via online messaging, telephone, video call, or face-to-face at UCL depending on your preference.**
- **This discussion can take up to 75 minutes.**
- **If you take part in an interview, you will be offered £11.25 via bank transfer or voucher, as a thank you for your time.**
- **Your answers will be pseudonymised and may be used to help to identify strategies that may be useful for autistic people in future.**

Want more information?

Please contact Rhiain Limby (Trainee Clinical Psychologist, UCL) by email at: ucjurpl@ucl.ac.uk to express interest.

The principal researcher for this study is Dr Richard Pender at UCL (Richard.pender.14@ucl.ac.uk). This study has been approved by the UCL Ethics Committee Project ID 24669/001.

Appendix D: Participant Information Sheet with Appended Interview Schedule Overview

Information Sheet

Thank you for showing interest in taking part in this research study. Please take time to read the below information carefully. If there is anything that is not clear or if you would like more information, you can contact the researcher, Rhiain Limby by email at ucjurpl@ucl.ac.uk. You can contact the Principal Researcher, Dr Richard Pender, at richard.pender.14@ucl.ac.uk. You can also show this page to someone else for advice if you want.

This is a new project that explores how autistic adults experience improvement in emotional difficulties. This may involve depression, anxiety, or any other form of emotional difficulties that you have experienced. We know that 'recovery', 'coping', or 'improvement' can be different for everyone, and we would like to understand more about how this is experienced by autistic adults. You are being asked to participate in this research study because you have received a diagnosis of autism or self-identify as autistic and from your perspective you have experienced improvement of emotional difficulties.

An overview of the interview schedule is attached as an appendix to this information sheet. You may find this helpful to gain more of an understanding of what the interview would involve.

This research project has been approved by the UCL Ethics Committee, the project ID number 24669/001.

Expressing interest in the project

If you would like to be considered to take part in the interview, you will be invited to complete an online initial screening questionnaire. This will include demographic questions (age, gender, and ethnicity), and some questionnaires; RAADS-14 (autistic traits questionnaire) and DASS-21 (measure of current distress). These questions help to ensure that this study is the right match before

you kindly donate your time and experiences. Demographic questions are included to ensure that we include people from a range of backgrounds. For this reason, we regret that we may not be able to invite everybody who expresses an interest to take part. You will be contacted after completing the questionnaire to arrange next steps for taking part or to let you know if you will not be able to take part on this occasion.

Your role in the project, and what you will be asked to do

Taking part in the research interview involves answering some questions about your experiences with improvement of the emotional difficulties you have identified. If you would like to know what kind of questions you may be asked, please view the interview schedule overview, which is attached in the appendix. However, this will not be exact as we may have some additional follow-up questions when we listen to or read your answers.

To make the experience as comfortable as possible, you can choose which communication method you prefer. You can choose to answer the questions via:

- The messaging function of Microsoft Teams
- Video call or telephone call
- Face-to-face in a private room at UCL

Whichever method you choose, you will only be speaking with the researcher (Rhiain Limby) during the interview. You can also choose to have a companion with you if you would like. This conversation may last up to 1 hour and 15 minutes. You will be offered £11.25 which you can choose to receive as bank transfer or voucher as a thank you for your time.

Sources of support

This study explores emotional difficulties such as anxiety and depression. Whilst the focus of the interview will be on overcoming and managing such difficulties, it may prompt thinking about difficult experiences. If you believe that you will find the interview distressing, it may not be appropriate to take part on this occasion in order to support your wellbeing. If you do decide to take part in the

study, the researcher will check in with you throughout to ensure that you feel happy to continue. It may be that you find the interview more emotionally upsetting than expected, in which case we will be happy to terminate the interview, remove any data you have shared (up until the point of anonymised transcription) and provide further support. You will be offered a debrief with the research team, and below is a list of services you can contact if you require additional support:

- If you or someone else is in danger, call 999 or go to A&E immediately.

- If you need help urgently for your mental health, but it's not an emergency, you can get help from NHS 111 online via https://111.nhs.uk/ or call 111.

- NHS Talking Therapies (which service you contact will vary depending on your local area, the research team will be happy to support you to identify the correct service). More information can be found here: https://www.england.nhs.uk/mental-health/adults/nhs-talking-therapies/

- National Autistic Society: NAS provides a range of information, resources, and support for the autistic community. The website can be accessed here: https://www.autism.org.uk/

- SHOUT is a free text-message based mental health support service. You can access this service by texting SHOUT to 85258. More information can be found here: https://giveusashout.org/

Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice. The information that is required to be provided to

participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task' and 'research purposes' will be the lawful basis for processing special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

How your data will be used

Screening Questionnaire

- The information you provide in the screening questionnaire will be used for recruitment purposes. If you are not invited to take part in the interview, this will be deleted. If you are invited to take part in the interview, it will be stored securely until the research has been completed (approx. September 2024), and then deleted.

Interview

- If using a verbal communication method, your research interview will be recorded using an encrypted voice recorder. After the interview is completed, this will be changed into a transcript (written format) for analysis and the voice recording will be deleted.
- If using a written communication method, the chat transcript will be downloaded and used for analysis.
- At this stage, your answers will be pseudonymised – meaning that it will be altered in a way that you can no longer be identified from the information alone, and your answers will instead be linked to a reference number which

is stored separately. This means that you would only be identifiable to the researcher, who holds access to the reference codes.
- The reference codes will be stored securely and separately.
- The transcripts will then be analysed to understand the key themes or ideas that are present in participants' experiences and produced in a written report.

All data will be stored securely on a password protected device in line with UCL's data management protocols. If you would like your data deleted post-participation, you may inform us before the data is transcribed and coded. After this point, your data will be pseudonymised and included in the written report.

The data collected during this research will help to add to research knowledge about autistic adults' mental health. This means that it could be used in journal articles, conference presentations, website content, or infographics to explain our results. If you would like to receive it, you will be sent a summary of the results once we have analysed the data.

About the research team

My name is **Rhiain Limby,** I am a Trainee Clinical Psychologist completing a doctoral degree at UCL. I am supervised by **Dr Richard Pender and Prof William Mandy.** Two autistic research consultants will also contribute to this project, by participating in two insight group meetings, taking part at both the design and analysis stages of the project. Together we aim to do research with and for the autism community.

Complaints procedure

If you would like to make a complaint, the process is as follows:

- In the first instance, please contact the Principal Researcher, Dr Richard Pender, at richard.pender.14@ucl.ac.uk.

- If you are not happy with how your complaint has been handled, you may contact the Chair of the UCL Ethics Committee at ethics@ucl.ac.uk.

As a research participant, you have the right to:

- Have your questions about the research answered.
- Understand what this research study involves and provide full consent.
- Change your mind about being a part of the research and withdraw from the study without explanation, provided it is prior to the pseudonymisation of data.
- Decline to answer or respond to any question that you are asked.

If you have considered the above information and would still like to take part in this study, you can complete the screening survey to express your interest. You can access this here:

https://forms.office.com/e/7diSqGdWc6

At the beginning of the survey is a consent form based on the above information. If you have any questions before completing the consent form, please email Rhiain Limby at **ucjurpl@ucl.ac.uk.**

Appendix E: Interview Schedule Overview Provided to Participants (included in advance with Participant Information Sheet)

Interview Schedule Overview for Participants

Thank you for taking part in this study.

Here is an overview of some of the types of questions that you may be asked. This is not an exact script, as you may not be asked all these questions in this order and/or you may be asked additional questions depending on your answers. The interview can last for up to 1hr 15 minutes, but you can choose to stop or ask for a break at any time without needing to provide a reason.

When you arrive, you will be introduced to the researcher (Rhiain Limby) and will have an opportunity to ask any questions before the interview begins. You can also let me know if any adjustments can be made to make you feel more comfortable.

1) **Current circumstances**
   - Can you describe your life at the present moment?
   - What do you enjoy doing? What's going well?

The next few questions are about what life was like for you since you started to experience emotional difficulties.

2) **Context of the emotional difficulties:**

- How would you like me to refer to the emotional difficulties that you experienced? Is there a particular word that best captures it? (e.g., stress, anxiety, depression)
- Thinking back to when it started, what did you experience when you first started noticing these emotional difficulties?
- Describing the physical/ emotional/ social experience?
- What was your life like then?
- Is there a specific word or phrase that you feel best captures this?
- Did you notice your difficulties or did someone else?
- Then what happened?
- How long did this experience last for?
- Why do you think you developed these emotional difficulties?
- Do you think being autistic played an important role in the development of your emotional difficulties?
- Why or why not?
- Do you think your autism has influenced how you experienced your emotional difficulties?
- How does your life differ now to when you first experienced these difficulties?

3) **Progress/ improvement:**

You've decided to take part in this study because you have had emotional difficulties in the past and you feel as though things have improved in some way since then. Could you tell me more about your improvement?

- How would you describe what improvement or progress is for you?

- What are the differences? (How you feel, behave, relationships etc)
- How would you know if you reached that stage?
- What would your improvement look like to the people around you?
- Has anybody commented on changes they have noticed in you?
- Are you hoping for further improvement with your emotional difficulties? What improvement would you like to see?
- Where do you consider yourself on that journey at the current moment?

4) Coping strategies:

Reflecting on the experience you have had so far, what were the most important factors that helped you?

These may include factors related to:

- Social (family/ friendships, relationships)
- Environment
- Leisure activities
- Services or Support Groups

- What type of therapy?
- What did you find most helpful about it?
  - Work or Education
  - Personal factors
  - Getting a diagnosis of autism
  - Religion or spirituality
  - Sensory
  - Medication/ substances
  - Other

- What do you think contributed to the helpfulness of those factors?
- Are there important aspects of your life currently that maintain your wellbeing?
- In what ways could you have been better supported in managing your emotional difficulties?
- If you had to summarise what helped you the most so far, what would be your top 3 factors?
- If another autistic person was experiencing the same emotional difficulties that you experienced, what would you suggest might be most helpful?
- Did you ever consider seeking formal mental health or wellbeing support? If no, why not?
- If yes, what was your experience like? What aspects were more or less helpful?

5) Threats to recovery/ improvement in wellbeing

- Are there aspects of your life that threaten your wellbeing?
- Are there certain factors that make it feel more difficult to maintain the improvements that you have noticed?

6) Views on 'recovery'

- Some people define recovery as no longer having any problems, while others might think about having tools to manage difficulties in day-to-day life. Others may have periods of time where things seem better, and periods where things become difficult again.
- Which of these fits best with your experience of what it means for your wellbeing to improve?

- Which do you think we should be aiming for when supporting autistic people with their wellbeing?
- Why do you think it is best that we view recovery this way?
- In your opinion, do we need to think about mental health recovery differently in the context of autism?

7) **Is there anything else that you feel is important in your experience that we have not talked about, that you would like to add?**

At the end of the interview, you will be thanked for your time and the researcher will explain next steps and will be happy to answer any further questions you may have.

Some of these questions may require you to think about difficult times in your life and this may feel upsetting. If you have found any aspect of the interview challenging, please speak with the researcher (Rhiain Limby) who will be happy to signpost you to ways of seeking emotional support.

Appendix F: Participant Consent Form

Improvement in anxiety, depression and related emotional difficulties amongst autistic adults

- Consent Form for Research Interview -

Name: _____

Date: _____

	Check the box if you agree with the statement
I understand what this research interview involves.	☐
I understand that my interview will be recorded for transcription purposes. If I choose to take part via chat function, the chat file will be saved.	☐
I understand that I can change my mind about taking part if I want to at any time, without giving a reason.	☐
I understand that I can have a companion with me during the interview if I would like to (e.g. a friend or family member).	☐
I understand that I can ask Rhiain Limby (ucjurpl@ucl.ac.uk) if I have any questions about the research now or in the future.	☐
I consent to take part in this research.	☐

ETHICS PROJECT ID NUMBER: 24669/001

Signature of research participant

(double click to type or add scanned signature)

X_____

Research participant

Date: Click or tap to enter a date.

Signature of researcher: Rhiain Limby

…… ***Date:***

Please return this form to Rhiain Limby (ucjurpl@ucl.ac.uk) who will be happy to advise on next steps.

ETHICS PROJECT ID NUMBER: 24669/001

Appendix G: Participant Debrief Sheet

Improvement in anxiety, depression, and related emotional difficulties amongst autistic adults

Debrief sheet

Thank you for taking part in this research project. Your responses will help to contribute towards research aimed at improving mental health support for the autistic community.

Below are contact details, should you need to make contact following the interview:

Contact details of Rhiain Limby, Trainee Clinical Psychologist: ucjurpl@ucl.ac.uk

Contact details of Dr Richard Pender, Clinical Psychologist and Principal Researcher: Richard.pender.14@ucl.ac.uk

Sources of support

If you find that you would like to access further support, please see the sources of support below:

- If you or someone else is in danger, call 999 or go to A&E immediately.
- If you need help urgently for your mental health, but it's not an emergency, you can get help from NHS 111 online via https://111.nhs.uk/ or call 111.
- You can make a referral to NHS Talking Therapies (which service you contact will vary depending on your local area, the research team will be happy to support you to identify the correct service). More information can be found here: https://www.england.nhs.uk/mental-health/adults/nhs-talking-therapies/
- National Autistic Society: NAS provides a range of information, resources, and support for the autistic community. The website can be accessed here: https://www.autism.org.uk/

- SHOUT is a free text-message based mental health support service. You can access this service by texting SHOUT to 85258. More information can be found here: https://giveusashout.org/

Complaints procedure

If you would like to make a complaint, the process is as follows:

- In the first instance, please contact the Principle Researcher, Dr Richard Pender, at richard.pender.14@ucl.ac.uk.
- If you are not happy with how your complaint has been handled, you may contact the Chair of the UCL Ethics Committee at ethics@ucl.ac.uk.

Appendix H: Example Procedure of Analysis

Initial Coding Example:

Transcript Excerpt:

“And I'm thinking right, OK, I have to be like that. I've gotta be those things and I've gotta be these other things. And very much trying to model myself off neurotypical family members, and nothing. I think that's turned out to be a nightmare because none of it seemed to work. I would always get so far, and I would think right, there’s something wrong with me. I’m getting depressed.”

Coded text:

Expectations	“I’m thinking right, OK, I have to be like that. I've gotta be those things and I've gotta be these other things.
Pressure to conform	“And very much trying to model myself off neurotypical family members”
Sense of failure	“I think that's turned out to be a nightmare because none of it seemed to work.
Self-blame	“I would always get so far, and I would think right, there’s something wrong with me.”
Depression	“I’m getting depressed.”

Theme Development Examples:

Codes	**Category**
Expectations Pressure to conform Masking Attempts to ‘fit in’ Attempts to avoid judgement from others	Pressure to conform
Sense of failure Self-blame Shame What’s wrong with me	Internalised ableism