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An investigation of the factors that contribute to the mental health and wellbeing of autistic adults

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Abstract

Autistic[1] people experience increased rates of mental health conditions and symptoms compared to their non-autistic peers; autistic women and trans people perhaps more so. However, there is not yet a consensus as to why this is the case. Through the lens of the neurodiversity paradigm, the present thesis aimed to develop an understanding of the factors that impact autistic people's mental health, from the perspective of autistic people themselves. First, this thesis presents a systematic review and thematic synthesis of the perspectives of autistic females on what experiences have impacted their mental health and wellbeing. Findings suggested that the biological and psychological factors associated with being autistic interact with a variety of environmental and social factors, in turn shaping wellbeing and mental health outcomes. Second, an empirical mixed-methods study is presented, which investigated mental health experiences and the factors that contributed to mental health and wellbeing in mixed-gender samples. The qualitative phase consisted of semi-structured interviews with 20 autistic adults and the quantitative phase investigated key factors identified by interviewees in a sample of 236 autistic adults using standardised questionnaires. High levels of depressive and anxiety symptoms and low levels of wellbeing were reported. Autistic cisgender women reported higher levels of anxiety, while autistic trans people reported more depressive symptoms. Feelings of exclusion and isolation, childhood bullying, autism-related stigma and challenges related to the neurotypical environment were all found to predict mental health and wellbeing. Overall, the findings of the present thesis point to the need for

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[1] Due to most participants in the present thesis (see Chapter 3) preferring identity-first terminology (50.2%) or having no preference (23.7%), identity-first language is used throughout this thesis.

community adaptations or interventions to create a more accessible and accepting society, as well as improvements in service provision for autistic adults.

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Overview

The aim of this thesis is to examine the factors that impact the mental health and wellbeing of autistic people, with a particular focus on understanding the experiences and perspectives of autistic women. This aim will be achieved across four chapters.

Chapter one will outline the theoretical underpinnings of the present thesis, with reference to the dominant models used to conceptualise autism and an outline of historical gender biases. It will also outline information in relation to the autistic population of Ireland. Finally, it will provide a broad overview of research in relation to autistic people’s mental health and how the present thesis aims to contribute to current knowledge.

Chapter two will report on a systematic review and thematic synthesis of the perspectives of autistic adolescent girls and women on what experiences shape their mental health, emotional wellbeing and social wellbeing. This review will present a formulation based on the perspectives of autistic girls and women, providing guidance for improving the mental health and wellbeing of this group, as well as suggestions for further research.

Chapter three will present an empirical mixed-methods study, consisting of a qualitative phase, followed by a quantitative phase, examining the factors that contribute to mental health and wellbeing of autistic adults across all genders. It will also estimate the levels of mental health symptoms and wellbeing within a sample of autistic adults living in Ireland.

The final chapter will summarise the findings of this thesis, outline its contribution to current knowledge, as well as discuss implications for clinical and community settings.

Chapter 1 - Introduction

1.1 Defining autism

Autism has traditionally been defined as a ‘disorder’ characterised by impairments and deficits, namely “persistent deficits in social communication and social interaction” and “restricted, repetitive patterns of behaviour, interests, or activities” (American Psychiatric Association; APA, 2013, p. 50). That is, this traditional medical model places the ‘problem’ within the individual and inherently seeks to prevent or treat said ‘problem’. An alternative way of viewing autism (and other disabilities) is through the lens of the social model of disability, which considers the individual within their context and defines the disability as a result of the interaction between an individual’s ‘impairments’ and the way society is organised, rather than within the individual (Oliver, 1983). This model has challenged traditional (individual or medical) approaches to disability and was initially developed largely through the work of disabled advocates throughout the 1960s and 1970s. While the phrase ‘social model of disability’ was first used by Mike Oliver, others have contributed to the development of variations in the social model of disability (e.g. Shakespeare & Watson, 2006). These variations share core elements, such as challenging individualised approaches to disability, addressing marginalisation and discrimination, and identifying and removing environmental/ societal barriers (Mallett & Runswick-Cole, 2014). In this view, autistic people are disabled as a result of an interaction between their particular needs and preferences, and an environment that cannot or does not accommodate these. Understanding autistic people in this way facilitates the implementation of accommodations and personalised supports, rather than creating an emphasis on individual therapies or prevention of autism.

The social model of disability is closely aligned with the neurodiversity paradigm, which also developed through the work of disabled (in this case autistic) self-advocates in response to the deficit-focussed view of autism (Happé & Frith, 2020; Pellicano & den Houting, 2022). Similar to the social model of disability, the neurodiversity paradigm acknowledges the interaction between inherent weaknesses (as well as differences) and the physical and social environment, which produces the disability (Kapp, 2020). The term ‘neurodiversity’ was coined by autistic sociologist Judy Singer in 1998, who described neurodiversity as part of the natural variety and diversity that exists within human neurodevelopment, similar to biodiversity within ecosystems (Singer, 1998). Thus, ‘neurodiversity’ itself is a term to describe the biological difference in human brains, whereby some individuals follow more common neurodevelopmental pathways, which are usually considered to fall within the range of ‘typical’ development (i.e. ‘neurotypical’) and others *diverge* from this standard in some (significant) manner, thus classifying them as ‘neurodivergent’ (Pellicano & den Houting, 2022). This includes a range of different types of neurodivergence, traditionally termed (neuro)developmental disorders within the medical model, including autism, Attention Deficit Hyperactivity Disorder (ADHD), dyslexia and developmental coordination disorder, among others. However, many feel that the scope of neurodiversity stretches beyond these groups and the boundaries of what ‘counts’ as neurodivergence remains unclear (Kapp, 2020). For example, psychiatric conditions such as schizophrenia or other acquired conditions, such as dementia are sometimes considered types of neurodivergence (Bertilsdotter Rosqvist et al., 2020). The term ‘neurodiverse’ can be used to refer to a group of individuals where different types of neurodevelopment are represented (e.g. a group of autistic, dyslexic and neurotypical individuals).

Neurodiversity itself is distinct from the 'neurodiversity paradigm', which refers to a particular set of approaches or beliefs about neurodiversity, which can be broken down into two key assumptions (Pellicano & den Houting, 2022). The first of these is the assumption that neurotyoical development is not superior or inferior to neurodivergent development and thus neurodiversity is valuable aspect of variation between humans (Pellicano & den Houting, 2022). The second assumptions states that all people deserve to be treated with dignity and respect, irrespective of their contribution to any collective purpose (Pellicano & den Houting, 2022).

Another important concept is that of the 'neurodiversity movement', which refers to the social justice movement seeking equality and full social inclusion for all neurodivergent people (Walker, 2021). Both prior to and since the coining of the term 'neurodiversity', autistic autism advocates have been the driving force of the neurodiversity movement. Many regard Jim Sinclair's 1992 influential essay 'Don't Mourn For Us' as central in the development of the autistic culture and community that eventually led to the neurodiversity movement (Milton, 2020; Pripas-Kapit, 2020). In this essay he addressed common concerns of parents with autistic children and challenged misconceptions:

> *"Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with"* (Sinclair, 1992, p. 1)

While the present thesis did not explore the neurodiversity movement, it was influenced by and conducted from the perspective of the neurodiversity paradigm.

Thus, while separate concepts, it is important to note the existence and influence of the neurodiversity movement, as its existence and on-going efforts have likely brought the neurodiversity paradigm into prominence within the academic domain in recent years (Pellicano & den Houting, 2022). In part it has done so by providing a platform for autistic scholarship (Milton, 2020), which has led to numerous autistic-led theories and concepts coming to the fore in mainstream academia, such as the Double Empathy Problem (Milton, 2017), and Monotropism (Murray, Lesser, & Lawson, 2005).

This is not to say that the neurodiversity paradigm rejects the traditional model entirely, but rather its deficit-focus is considered too narrow (Pellicano & den Houting, 2022). In fact, the neurodiversity paradigm acknowledges the interaction between inherent weaknesses (as well as differences) and the physical and social environment, which produces the disability (Kapp, 2020). In addition, it supports medical intervention for co-occurring conditions, while strongly opposing treatments for autism itself:

> *"The neurodiversity movements' opposition to "curing" autism has produced misunderstandings, such as mistaken assumptions that it attributes all challenges to social injustices and rejects interventions to mitigate them"* (Kapp, 2020 p. 8)

It prioritises the quality of life of the individual and works back from there to identify the individual *and* environmental factors that interact to produce disability, rather than presuming a linear relationship between weaknesses/ differences and disability (Kapp, 2020). Thus, the neurodiversity paradigm supports both individual interventions (e.g. therapy to build language) and social interventions (e.g. laws prohibiting discrimination; Kapp, 2020). However, it does differ from the traditional paradigm in terms of the types of interventions it supports. For example, it does not support the principles or practices of some well-established forms of individual therapy, e.g. Applied Behaviour Analysis (Dawson, 2004), nor does it support a focus on reducing autistic traits (e.g. stimming [stereotyped motor movements, which serve self-regulatory and self-soothing purposes; Kapp et al., 2019]) in pursuit of a more neurotypical presentation.

In sum, within the neurodiversity paradigm, autism can be characterised by *"atypical communication, intense and "special" interests, a need for familiarity or predictability and atypical sensory processing"* (Kapp, 2020, p. 9), which directly mirrors the DSM-5 criteria, though using more neutral language.

While the neurodiversity paradigm attempts to address isses within the traditional view of autism, it is not without its own criticisms. One such criticism is that the neurodiversity paradigm does not adequately represent those with high support needs and/ or co-occurring intellectual disabilities and thus it is not representative of the neurodivergent population as a whole (Russel, 2020). That is, while the neurodiversity paradigm opposes treatments for autism, other autistic individuals (and/ or their parents) wish to alleviate the challenges associated with being autistic and therefore advocate for identifying and implementing effective treatments. Another common criticism of the neurodiversity paradigm is the lack of consensus around how neurodivergence is defined and thus who fits into this category (Russel, 2020). While it is generally well accepted that those with neurodevelopmental conditions can be classified as neurodivergent, there are mixed opinions on whether those with acquired conditions (e.g. dementia, schizophrenia) fit within the definition of neurodivergent (Russel, 2020). As such, the applicability of the neurodiversity paradigm and the concepts related to it require further exploration and investigation as the field continues to develop.

1.2 Neurodiversity and clinical psychology practice

The scientist-practitioner model underpins the training and practice of clinical psychologists in Ireland and in other countries across the world (Carr, 2012). It posits that clinical psychologists should be trained as both scientists and practicing professionals, with the desired outcome of clinical psychologists basing their assessments and interventions on knowledge derived from high quality research, as well as contributing to the evidence base themselves through conducting and publishing research (Carr, 2012). Given that research on neurodiversity and particularly its application to clinical practice is in its infancy, there is not sufficient evidence to suggest that a shift to the neurodiversity paradigm is warranted for clinical psychologists. However, many interventions provided by psychologists and the principles that underpin them are indeed aligned with the neurodiversity paradigm. For example, Positive Behaviour Support (PBS) is an approach to reducing 'behaviours that challenge' for autistic people (typically those with a co-occurring ID) primarily through increasing an individual's quality of life and expanding their skillsets, with a particular emphasis on person-centred values when developing appropriate individualised interventions (Carr et al., 2002). Thus, PBS can be implemented in a neurodiversity affirmative manner, for example through focussing on antecedent-based interventions, providing access to activities of interest and engaging with the individual around what skills/ knowledge they would like to acquire.

The scientist practitioner model also dictates that clinical psychologists must remain informed of recent developments in research relevant to their field of work

(Overholser, 2010). Thus, it is important for clinical psychologists to be aware of the emerging research around the neurodiversity paradigm. For example, they should be aware of clients' potential preferences around language or types of interventions and they should maintain a working knowledge of how environmental factors can play a role in autistic people's functioning or wellbeing. Indeed, an important aspect of the neurodiversity paradigm is the focus on the social and environmental changes that are necessary for the full inclusion of autistic people in society (and thus their wellbeing). While societal change and social advocacy have not traditionally been part of the role of a clinical psychologist, there has been a significant shift in recent years, for example through the development of community psychology practice (e.g. see Walker, Zlotowitz, & Zoli; BPS, 2018). Thus, clinical psychologists may now be well placed to act as advocates for autistic people, especially for change that will be beneficial to their mental health and wellbeing.

1.3 Autism in females and other genders

It was largely the work of Leo Kanner (1943) and Hans Asperger (1944) that eventually led to the development of 'autism' as a diagnostic concept. However, both Kanner and Asperger based their observations largely on samples of young boys. Thus, since its inception autism has been defined and understood as a male experience, creating biases that continue to impact autistic people of other genders. Many autistic women and girls are not identified as autistic in childhood or adolescence, with one study showing that females are diagnosed almost 4 years later than males (Huang et al., 2021). Instead, many women receive a diagnosis or self-identify as autistic much later in life, after spending years struggling to understand themselves and finding somewhere they fit in (Lai & Baron-Cohen, 2015; Rivet & Matson, 2011; Sedgewick, Crane, Hill & Pellicano, 2019). As a result, autistic women have often been under-represented in research and their experience is often not well represented within the professional or layperson understanding of autism.

Some research has proposed the existence of a specific 'female autism phenotype' (FAP), distinct from the presentation of autism in males, which explains why autism is not identified in females in a timely way (e.g. Hiller et al., 2014; Mandy et al., 2012). In a recent narrative review on the subject, Hull and colleagues (2020) identified four characteristics commonly considered aspects of the FAP:

1. Autistic females are believed to have less difficulty with social relationships, whereby they have higher social motivation and tend to be able to develop friendships more easily than autistic males. However, they may experience challenges maintaining long-term friendships and managing interpersonal conflict.
2. Some research has suggested than autistic females' special interests are less intense and/ or more age or gender 'appropriate'.
3. Autistic females are more likely to experience internalising problems (e.g. anxiety, eating disorders), compared to externalising problems (e.g. behavioural difficulties), which are more common among autistic males.
4. Autistic females appear to engage in increased levels of masking. Masking can be defined as either consciously or unconsciously concealing one's autistic responses in favour of responses that are more socially desirable, in the areas of social interaction, behaviour, cognition and sensory experiences (Pearson & Rose, 2021). It has also been referred to as 'camouflaging', with sub-components of masking, compensation and assimilation (Hull et al., 2017). In line with the preferences of the autistic community, the term masking will be

> used throughout this thesis as an umbrella term to describe this range of experiences (Pearson & Rose, 2021).

While describing a FAP may be useful to clinicians completing autism assessments with females who present in this way, there are also important criticisms to note, including how the concept of the FAP appears to ignore the possibility of a general heterogeneity in autism, as well as inevitable social influences on how individuals present, on which gender likely has a significant impact (Pearson & Rose, 2021). In line with this, Rose (2020, as cited in Pearson & Rose, 2021, p. 57) summarised *"Autistic women and girls don't experience different autism, they experience different prejudice"*. In addition to 'different prejudice', autistic females may also have different experiences in relation to hormones (e.g. the menopause; Moseley et al., 2020), delayed diagnosis (Bargiela et al., 2016) and sexual victimisation (Pecora et al., 2020), which likely also impact on their emotional and behavioural profiles. In sum, while the FAP is an important theory to consider, a broader view of heterogeneity within autism and consideration of social influences are other ways to make sense of alternative presentations.

A further central issue in relation to gender and autism is the experience of autistic trans people. The term 'trans' is used here and throughout this thesis when referring to groups of individuals who do not identify with the sex they were assigned at birth, as per guidelines provided by the Transgender Equality Network of Ireland (n.d). However, when a particular individual is mentioned, their specific gender identity (e.g. non-binary) will be used. In recent years, as societal understanding of gender diversity has developed, research has shown that there is an increased number of trans people in the autistic community compared to the population as a whole (van der Miesen et al., 2018; Walsh et al., 2018). Furthermore, this group report high levels of discrimination and social isolation, as well as mental health difficulties more significant than cisgender autistic people (Cooper et al., 2020; Murphy et al., 2020). Thus, particular attention should be given to understanding autistic people of all genders when conducting research with autistic individuals (Dewinter et al., 2020).

1.4 Autistic people in Ireland

It is estimated that approximately 1 in 66 children in the Republic of Ireland are autistic (Boilson et al., 2016), which is relatively comparable to current international estimates (1 in 44 according to the Centre for Disease Control; CDC, 2022; 1 in 100 according to the World Health Organisation; 2022). However, a recent report based on the ‘Northern Ireland School Census’ indicated that 4.7% of children aged 4 - 15 had an official diagnosis of autism, which translates to 1 in 22 school-aged children being autistic (Rogers & McCluney, 2022). Less information is available with regard to the number of autistic adults in Ireland or internationally. The CDC has estimated that the adult prevalence in the USA is 2.21%, but reliable prevalence figures for Ireland or the UK are not available, to the best of my knowledge. As our understanding and thus the identification of autism improves, it will be important to accurately estimate the number of autistic people living in Ireland, so as to appropriately plan for the required services or supports.

In terms of sex ratio, the most widely accepted ratio in Ireland and the UK is currently 3:1 (male: female), which is a figure derived from a systematic review and meta-analysis of the autism sex ratio in childhood and adolescence conducted in 2017 (Loomes, Hull, Mandy, 2017). However, due to the aforementioned diagnostic biases against identifying females, it is believed by some that this ratio is lower. There have been fewer studies conducted examining the autism sex ratio in adulthood, but some have shown that the sex ratio descreases with age, suggesting that delays in diagnosing females may account for a portion of the larger sex ratio observed in childhood and adolescence (May & Williams, 2018; Rutherford et al., 2016). There are currently no statistics outlining the sex ratio of the autistic population in the Republic of Ireland, though Ireland's National Autism Charity (AsIAm) stated in a 2021 report that responses to a parent survey garnered responses in line with a sex ratio of less than 3:1. Further, they go on to caution against considering this true estimate of the gender ratio, citing diagnostic biases against girls (AsIAm, 2021). Thus, while the true sex ratio in Ireland (and around the world) is currently unknown, it is fair to conclude that autistic girls and women are under-diagnosed and increased understanding of this group is essential in order to resolve this issue.

1.5 Autistic mental health & wellbeing

Autistic people experience mental health conditions at a disproportionate rate when compared to their non-autistic peers; a recent systematic review of studies reporting rates of mental health conditions based on formal diagnoses (according to DSM or ICD criteria) indicated that there is a 20% current prevalence of anxiety disorders and an 11% current prevalence of depression (Lai et al., 2019). Moreover, their risk is not limited to anxiety and depression; increased rates are observed across a wide range of conditions, including obsessive-compulsive disorder, bipolar disorder, psychotic disorders and eating disorders (Huke et al., 2013; Hollocks et al., 2019; Lai et al., 2019; Zheng et al., 2018). Indeed, the prevalence of mental health conditions among this population is well established and has been described as *"the autism mental health crisis"* (Mandy, 2022, p. 1), with researchers, clinicians and community members calling for decisive action (e.g. Authentically Emily, 2021; Mandy, 2022). It should be noted that autistic people often experience co-occurring conditions, such as

ADHD and epilepsy, which can increase their risk of experiencing mental health difficulties (Smith & Matson, 2010; Pehlivanidis et al., 2020).

Aside from experiencing common mental health conditions, autistic people can also experience unique symptoms or conditions indicative of poor mental health. One such experience is ‘autistic burnout’, which has been described extensively by autistic people via social media and blogs (e.g. Boren, 2017; Rose, 2018), but had not been explored in the academic literature until recently (Raymaker et al., 2020). Autistic burnout is a debilitating condition most often caused by a build-up of daily life stressors and a mismatch between individual abilities and societal expectations. It is characterised by exhaustion, withdrawal and reduced functioning abilities (Higgins et al., 2021; Raymaker et al., 2020). Other unique autistic experiences are ‘meltdown’ and ‘shutdown’; both experiences involve feeling entirely overwhelmed and a loss of control (Welch et al., 2021; Phung et al., 2021), where ‘meltdown’ describes an outward expression of anxiety and energy (Welch et al., 2021), and ‘shutdown’ involves withdrawal and loss of functioning (to varying degrees; Belek, 2018).

A recent editorial on the autism mental health crisis outlined practical suggestions for addressing the crisis. These included strategies for both prevention and treatment of mental health difficulties and emphasised the importance of partnerships between researchers, clinicians and the autistic community (Mandy, 2022). When planning prevention strategies, it is essential to understand the reasons that autistic people develop mental health difficulties and in line with the neurodiversity paradigm, it is important to consider both individual and the broader social factors that may impact mental health.

1.6 Participatory research

Participatory research methods incorporate the views of autistic people with regard to what research gets done, how it is carried out and how the findings are applied (Fletcher-Watson et al., 2019). It is intended to ensure that the priorities of autistic people are at the centre of research decisions, as well as to improve the quality and utility of research outcomes (Fletcher-Watson et al., 2019; Pickard et al., 2022). It also acknowledges, in line with standpoint theory (Harding, 1991), that autistic people are a marginalised group, whose experiences are often not well understood by those outside of this group. Though in contrast to standpoint, the present thesis does not seek to achieve objectivity, but rather takes a critical realist approach. Thus, as a neurotypical researcher seeking to understand the experiences of autistic people, I acknowledge that I am likely not best placed to conduct this research and translate the findings. In order to improve the relevance and validity of this thesis I consulted and worked closely with autistic colleagues and community members to varying degrees throughout the research process. The specific roles of these individuals will be described within chapters two and three.

1.8 Contribution of this thesis to current knowledge

Evidence clearly demonstrates that autistic adults experience more mental health difficulties than non-autistic adults (Cassidy et al., 2018; Hollocks et al., 2019; Lai et al., 2019), autistic women and trans people perhaps more so (Lai et al., 2019; Murphy et al., 2020). However, there is currently no consensus in the scientific literature as to the reasons for this. Several theories and models offer explanations, including cognitive theories that implicate sensory differences and ‘intolerance of uncertainty’ (e.g. Stark et al., 2021) and socially-oriented models, such as the minority stress model, which describes how factors associated with a stigmatised identity impact mental health (Botha & Frost, 2020). What appears to be lacking in the current literature is a comprehensive investigation into autistic perspectives on the matter. This is not to say that the evidence does not exist, but arguably it exists in a piece meal fashion. That is, there are many studies examining autistic experiences related to mental health (e.g. masking; Hull et al., 2017, trauma; Kerns et al., 2022), but none which explicitly ask the question "what experiences in life have impacted your mental health?", thereby considering autistic people experts in their owns experiences, as well as autism experts more generally (Gillsepie-Lynch et al., 2017).

Research on this topic in relation to autistic girls and women is even less available, though we do know that autistic females have some unique experiences that are believed to impact their mental health. Thus, their experiences require specific attention, distinct from their peers of other genders. As described above, using the neurodiversity paradigm as a framework allows research to gain a fuller understanding of autism, to take into account the strengths (as well as weaknesses) of autism and to consider the interaction between the individual and their physical and sociocultural environment when making practical recommendation.

1.9 Thesis aims

Using the neurodiversity paradigm as an overarching framework, the present thesis aims to understand autistic people's perspectives on the factors that impact their mental health. To my knowledge, no research has been conducted previously that seeks to directly explore the perspectives of autistic people on the full range of factors that impacts their mental health, without a predetermined focus (e.g. masking, trauma).

This thesis presents a Systematic Review and empirical mixed-methods study examining autistic people's perspectives on their experience of mental health and the factors that impact their mental health. As will be evidenced in the Systematic

Review, many studies have, through the exploration of other topics, touched upon various factors that impact autistic people's mental health. As such, the first study aimed to extract the perspectives of autistic people from these pre-existing studies. In order to first gain an understanding of the under-studied group, autistic females were the focus of this study, whereby the self-reports of autistic females were extracted from the existing qualitative literature in order to answer the following main research question:

- What is the existing evidence base of factors that contribute to the mental health, emotional wellbeing and social wellbeing of autistic women and adolescent girls, according to qualitative self-reports?

Next, the empirical mixed-methods study sought to understand the perspectives of autistic adults of all genders with regard to the factors that have impacted their mental health. Targeted recruitment sought to provide a level of gender balance within the sample. This included a qualitative phase involving one-on-one interviews with autistic people to explore their mental health experiences and the factors that influenced their mental health, followed by a quantitative phase which examined the predictive ability of key factors identified by interviewees, using a survey of standardised questionnaires with a larger sample of autistic adults living in Ireland. This study aimed to answer the following key research questions:

- What are the experiences of and levels of mental health difficulties and mental wellbeing in a mixed-gender convenience sample of autistic adults (without an ID) living in Ireland? Do the levels of mental health symptoms and mental wellbeing vary depending on gender?
- What factors contribute to the mental health and wellbeing of autistic adults in Ireland?

Chapter 2 - Perspectives of autistic adolescent girls and women on what experiences contribute to their mental health and emotional and social wellbeing: A systematic review & thematic synthesis of lived experience

Abstract

Autistic girls and women experience more mental health difficulties and poorer wellbeing than their non-autistic peers and while theories attempt to explain this, little emphasis has been placed specifically on the perspectives of the girls and women within the literature. This review aims to provide an overview of the factors described by autistic females in qualitative studies that impact their emotional and social wellbeing and mental health. The protocol for the present review was pre-registered on PROSPERO (CRD42020184983) and this article follows PRISMA guidelines. PsycInfo, Academic Search Complete and MEDLINE were systematically searched using a pre-defined search string. This yielded 728 unique records, which were systematically screened by two reviewers, resulting in 41 eligible studies. Structured data extraction and quality appraisal were completed. The present review presents the perspectives of 690 autistic females aged 13 – 70+. Thematic synthesis identified 9 themes and 31 sub-themes that describe experiences that have impacted on mental health and wellbeing. Our findings suggest that autistic girls' and women's experiences can be conceptualised within a social model, where biological and psychological factors ('The Autistic Neurotype') are experienced through the lens of a range of social factors ('The Neurotypical World' and 'Stigma'), together shaping wellbeing and mental health outcomes. This review indicates that the key to improving the mental health and wellbeing of autistic girls and women lies within communities and society as a whole. Future research could focus on gathering the

experiences of autistic people of all genders to better understand the development of their mental health and wellbeing.

2.1 Introduction

Autism has traditionally been viewed as a disorder, understood through the lens of the medical model. This view identifies ‘deficits’ within autistic people (APA, 2013) and works towards a prevention or treatment of autism or its features (e.g. Green et al., 2017; Gulsrud & Renno, 2021). However, in recent years a re-framing of autism as a type of neurodivergence with a range of traits and characteristics that are different, but not inferior to neurotypical ways of being, has become more widely accepted (Happé & Frith, 2020). Within the neurodiversity framework, autism can be defined as a neurotype characterised by differences compared to the non-autistic population in a variety of areas, such as social approach, cognitive style and sensory processing (Kapp, 2020). While the medical model describes deficits in autism, such as “abnormal social approach” and “highly restrictive, fixated interests that are abnormal in intensity or focus” (APA, 2013, p. 50), the neurodiversity paradigm values autistic social approach as a valid alternative to neurotypical social preferences and views these “restrictive” interests as strong passions that can become areas of expertise. The present review will be conducted from the perspective of the neurodiversity paradigm.

The eventual development of ‘autism’ as a diagnostic concept can be traced back to the work of Leo Kanner (1943) and Hans Asperger (1944), who both based their observations largely on young boys. As such, a bias towards identifying and understanding autistic males existed from the very outset, with the existence and experiences of autistic girls and women often being overlooked. As a result, to this day, many autistic girls and women are not identified, or receive a diagnosis later in life, after spending many years confused about why they don’t feel they fit in (Lai & Baron-Cohen, 2015; Rivet & Matson, 2011; Leedham et al., 2020). As well as regular missed diagnoses, other difficulties that autistic girls and women face are becoming evident in the literature, such as more interpersonal conflict within friendships (Sedgewick, Hill, & Pellicano, 2019), increased vulnerability to sexual victimization (Percora et al., 2020) and distress related to constant efforts to suppress their natural responses in favour of more a ‘neurotypical’ presentation in order to avoid stigmatisation by society (i.e. known as ‘masking’; Pearson & Rose, 2021; Cook et al., 2021). Perhaps most alarmingly, autistic girls and women experience mental health difficulties, such as anxiety disorders and depressive disorders, at a disproportionate rate when compared to their non-autistic peers (Angell et al., 2021; Lai et al., 2019). Furthermore, they report higher levels of depression than autistic males at all stages of life (Lai et al., 2019; Oswald et al., 2016) and may have higher levels of anxiety (Angell et al., 2021; Sedgewick et al., 2021; Uljarević et al., 2019), though some research shows no significant difference (Cage et al., 2018; Lai et al., 2019; Hull et al., 2021). In addition, autistic women are five times more likely to attempt suicide than their non-autistic counterparts and more than twice as likely as autistic males. Specifically, it was estimated that almost 14% of autistic women without a co-occurring intellectual disability (ID) had attempted suicide, while this figure increased to over 20% for women who also have ADHD (Hirvikoski et al., 2020). In addition to experiencing mental health difficulties, autistic women report lower levels of positive psychological wellbeing and quality of life than their non-autistic counterparts (Cai, Richdale, Dissanayake, & Uljarević, 2020; Mason et al., 2018).

In order to truly understand the wellbeing of autistic people, we must understand what wellbeing means to autistic people. Milton and Sims (2016) set out to explore the meaning of wellbeing for autistic adults, with a particular emphasis on the social aspects of wellbeing. In this study they identified key themes of having personal needs met (including minimising stress), societal othering, connecting with others and managing relationships. As such, alongside emotional wellbeing, social wellbeing (constructed from an autistic viewpoint) is a key element of autistic wellbeing. In neurotypical contexts, emotional wellbeing can be described as the increased experience of positive emotions, such as joy, relaxation or vigour, and fewer experiences of negative emotional states, such as sadness, worry or lethargy (Seligman, 2011). In addition to this, the autistic perspective emphasises the importance of minimising stress (Milton & Sims, 2016). For neurotypical people, social wellbeing can be defined as receiving adequate support from others, feeling loved and valued and feeling satisfied with one's personal relationships (Seligman, 2011). The autistic perspective also includes the experience of social inclusion (vs. social exclusion) as part of their social wellbeing (Milton & Sims, 2016). For example, they identified that acceptance and celebration of their autistic identity was important for their social wellbeing, while experiences of bullying and stigma were indicative of poorer social wellbeing. Given that the concept of autistic wellbeing has not yet been conclusively defined, the present review will employ definitions that use a combination of standard definitions of emotional and social wellbeing and the description of autistic wellbeing, as outlined by Milton and Sims (2016).

2.1.1 Aims & objectives of the present review

This review aims to gain an understanding of the factors that impact on the emotional wellbeing, social wellbeing and mental health of autistic girls and women, from the perspective of autistic girls and women themselves. This will be achieved by synthesising qualitative studies on the lived experiences of autistic girls and women. It is hoped that by synthesising the reports of autistic adolescent girls and women, the present review will provide a clearer picture of what causes poorer wellbeing and mental health difficulties, helping us to understand how to prevent these difficulties from occurring in the first place. It will also offer a platform for future research to develop that is more in line with the perspectives of these girls and women.

The present review will comprise qualitative self-report studies, where autistic adolescent girls and women discuss their own experiences, specifically experiences that have impacted their mental health, emotional wellbeing or social wellbeing.

The present review primarily aimed to answer the following research question: What are the self-reported determinants of mental health, emotional wellbeing and social wellbeing in autistic adolescent girls and women?

2.2 Methods

A protocol for this study was pre-registered on PROSPERO (CRD42020184983;https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020184983). The current article adheres to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021; see Appendix A).

2.2.1 Data sources and search strategy

Three electronic databases (PsycINFO, Academic Search Complete and MEDLINE) were searched using a pre-defined search strategy, as outlined in Table 1.

The resulting studies were imported into Covidence, where duplicates were removed and the screening process was conducted in accordance with the pre-defined eligibility criteria below.

A pre-planned search strategy was developed using the SPIDER search strategy tool, which culminated in the search terms in Table 1. Preliminary searches aided the development of the final search terms.

The initial searches were conducted between July 3rd and 17th 2020. 780 records were identified, reducing to 622 when duplicates were removed. The searches were run again in on the 2nd of April 2021 to identify any new papers published since July 2020, which yielded another 106 studies for screening. Unpublished "grey" literature was not included in the present study.

Table 1

Search strategy for systematic review

		PsycINFO	**Academic Search Complete**	**MEDLINE**
S – Sample	Autistic [abstract] adolescent girls and women [anywhere]	ab(Autis* OR asd OR asperg*) AND (female OR wom*n OR girl* OR gender OR sex)	AB(Autis* OR asd OR asperg*) AND TX(female OR wom*n OR girl* OR gender OR sex)	ab(Autis* OR asd OR asperg*) AND (female OR wom*n OR girl* OR gender OR sex)
PI – Phenomena of Interest	Mental health and wellbeing	ab(Mental health OR stress OR distress OR wellbeing OR well-being OR wellness OR anx* OR depress* OR quality of life OR happ* OR mood OR feel* OR content* OR love* OR satisf* OR mask* OR camouflag* OR compensat* OR pretend* OR	AB(Mental health OR stress OR distress OR wellbeing OR well-being OR wellness OR anx* OR depress* OR quality of life OR happ* OR mood OR feel* OR content* OR love* OR satisf* OR mask* OR camouflag* OR compensat* OR pretend* OR	ab(Mental health OR stress OR distress OR wellbeing OR well-being OR wellness OR anx* OR depress* OR quality of life OR happ* OR mood OR feel* OR content* OR love* OR satisf* OR mask* OR camouflag* OR compensat* OR pretend* OR

		belong* OR bully* OR victim* OR isolat* OR stima*)	belong* OR bully* OR victim* OR isolat* OR stima*)	belong* OR bully* OR victim* OR isolat* OR stima*)
D – Design	Description of lived experience	(Interview* OR focus group* OR survey OR question*)	TX(Interview* OR focus group* OR survey OR question*)	(Interview* OR focus group* OR survey OR question*)
E – Evaluation	Experiences	(Experience* OR difficult* OR descri* OR express* OR discuss* OR view* OR opinion* OR belie* OR perce* OR attitude*)	TX(Experience* OR difficult* OR descri* OR express* OR discuss* OR view* OR opinion* OR belie* OR perce* OR attitude*)	(Experience* OR difficult* OR descri* OR express* OR discuss* OR view* OR opinion* OR belie* OR perce* OR attitude*)
R – Research type	Qualitative and mixed methods	(Qualitative OR mixed method*)	TX(Qualitative OR mixed method*)	(Qualitative OR mixed method*)

2.2.2 Eligibility criteria

Eligibility criteria were developed in order to identify studies in which the qualitative accounts of autistic adolescent girls and women could be extracted and analysed. Eligibility criteria can be categorised into three of the relevant elements as outlined by PRISMA (participants, study design and concepts). A final element relating to the manuscript was added (see Table 2). Where a study met all other eligibility criteria, but it was unclear which findings were applicable to females, corresponding authors were contacted in an effort to gather the necessary information to allow the extraction of data applicable to the female participants. Where no response from authors was received, the study was excluded.

Concepts of interest to the current review were mental health, emotional wellbeing and social wellbeing. These concepts are operationalised as follows for the purposes of this review. Mental health can be defined as any symptomology typically related a mental health condition, without the need to meet any formal criteria for a mental health disorder. For example, discussion of anxiety, low mood, fatigue, restricted eating, physical symptoms with no apparent organic cause. The operationalisation of wellbeing draws on Seligman's PERMA model, as well as the World Health Organisation definition of psychological wellbeing (WHO-5) and research on autism-specific wellbeing (WHO-ASDQoL; Milton & Sims, 2016). As such, 'emotional wellbeing' (mapped onto PERMA's 'Positive emotion') can be defined as experiencing positive emotions (e.g. joy, positivity, calm, relaxation, vigour, etc.) versus the experience of negative emotions (e.g. stressed, low, worry, anxious, tired, lethargic, etc.). 'Social wellbeing' (mapped into PERMA's 'Relationships') can be defined as receiving help or support from others when needed, feeling loved, feeling satisfied with personal relationships (family, friends, romantic partners, colleagues, classmates), feelings of social inclusion and belonging versus feeling socially ‘othered’ (e.g. bullied, victimised, isolated, stigmatised). See Table 2 for a full overview of eligibility criteria.

Table 2

Eligibility criteria for systematic review

	Inclusion	Exclusion
Participants	• Participants have a formal or self-diagnosis of autism, autism spectrum disorder or Asperger’s Syndrome • There must be a minimum gender ratio of 1:3 (female:male) OR a minimum of 5 female participants • If there are participants of other genders in the study, there is gender differentiated analysis or it is clear in the results which findings and quotes apply to females • All relevant participants in a study must be 13 years old or above	• Gender of participants is not identified or stated clearly in the results/ findings • Studies with a primary research question around gender dysphoria or trans-gender identity • Participants are informants (e.g. family members, carers, partners), rather than self-report.

	• Autistic girls/ women reporting their own experiences (they can be supported by a family member, carer or other).	
Study design	• Qualitative or mixed-methods study • Data collected via interviews/ focus groups/ written responses to open-ended questions/ collecting pre-existing material (e.g. diary entries or personal essays)	• Studies with a quantitative design
Concepts	• Discussion of life experiences that have impacted mental health, emotional wellbeing and/ or social wellbeing.	• Intervention study*
Manuscript	• English language • Published in a peer reviewed journal	

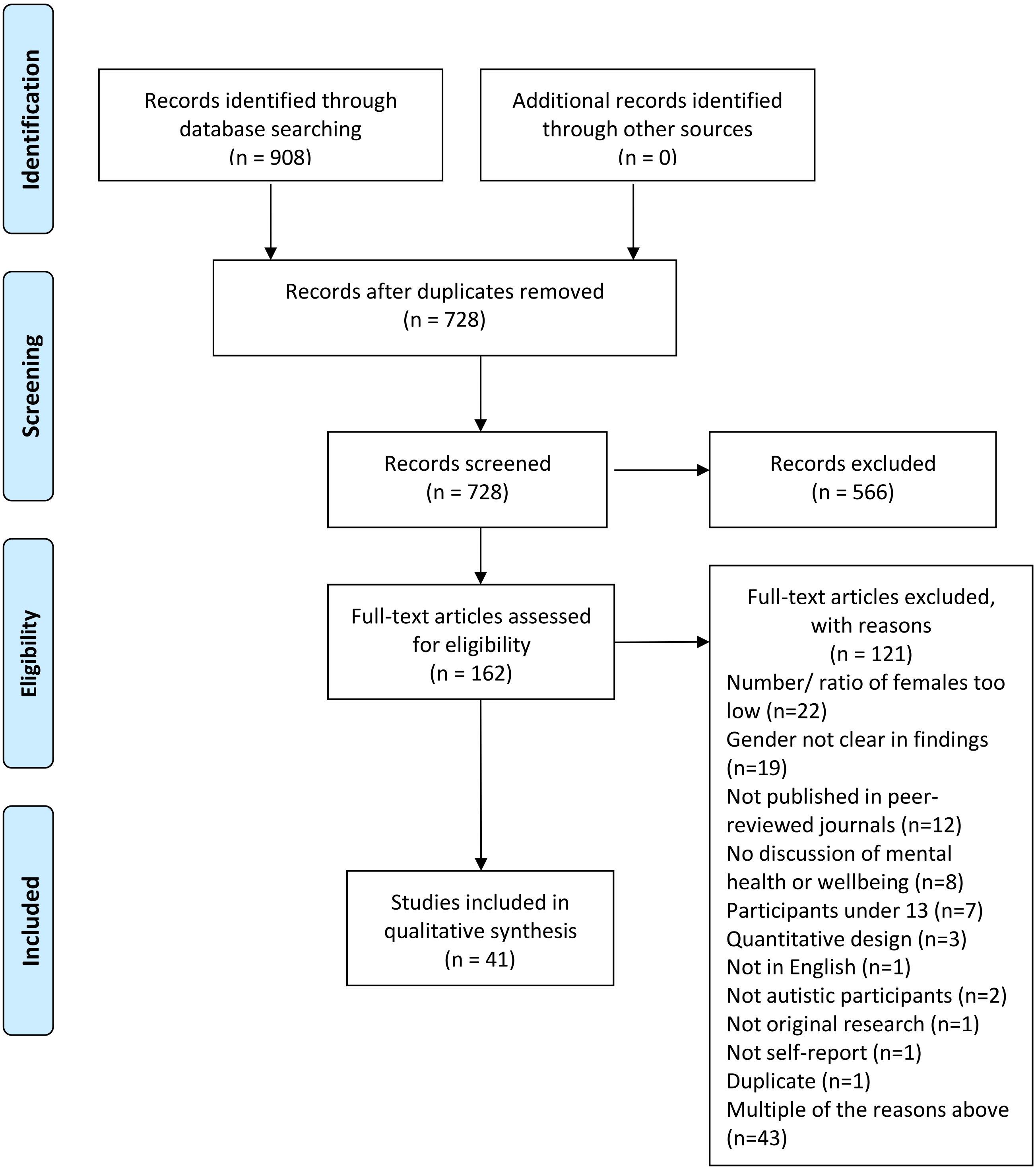
*criteria clarified during the screening stage (not specified in PROSPERO protocol)

2.2.3 Screening and study selection

The screening and selection process was conducted through Covidence. All 728 titles and abstracts were screened by ROC for possible inclusion. A random 20% sample of these abstracts was also screened independently by TRE. Inter-rater reliability was substantial (Cohen’s kappa = 0.80). Abstracts for which a disagreement emerged were automatically included for full-text screening. 162 full texts were screened for possible inclusion independently by both ROC and TRE. Inter-rater reliability was acceptable (Cohen’s kappa = 0.69). All disagreements were discussed with a third reviewer, KG, in order to make a final decision of inclusion versus exclusion. Reasons for exclusion at full text screening stage are detailed in the PRISMA diagram (see Figure 1). As a result of the full text screening, 41 studies were included in the current review.

Figure 1

PRISMA flow diagram



2.2.4 Data extraction and thematic synthesis

Data from the included studies were extracted using an adapted version of the Joanna Briggs Institute data extraction form (see Appendix B). It was used to extract data from included studies, such as participant characteristics, method of data collection and method of analysis. This process was completed by ROC. Next, data for the thematic synthesis were extracted by identifying text within the 'Results' or 'Findings' sections of included studies and copying paragraphs for sections that discuss life events or experiences that have impacted on the participants' mental health, emotional wellbeing or social wellbeing. This included text such as descriptions of the results (e.g. thematic analysis) direct quotations from participants or summaries of findings. The resulting text formed the data for the thematic synthesis. Parallel to data extraction, each included study was evaluated by ROC using the National Institute for Health and Care Excellence Qualitative Quality Appraisal checklist (see Appendix C). No studies were excluded on the basis of the quality assessment, as all studies were of medium or high quality.

Thematic synthesis, as described by Thomas and Harden (2008), was used to analyse the data, in order to gain understandings from the data, which go beyond the findings of the original papers. ROC and MD undertook this collaboratively. Having two researchers from different backgrounds (one of whom is autistic) allowed for increased rigor and the development of deeper understandings. The thematic synthesis took the form of a three-stage process. First, ROC and MD independently completed line-by-line coding of the text. Codes were created inductively, to capture the meaning and content of each sentence, sometimes applying more than one code to one statement. A final bank of codes was developed by ROC based on initial codes assigned by each reviewer. MD reviewed this final bank of codes alongside the corresponding data. Any disagreements were discussed until resolved. Next, ROC analysed codes for similarities and differences and then grouped them together accordingly, assigning new labels to groups of codes. MD completed this process for 20% of codes and the resulting groups of codes for this portion of the data were compared and discussed by ROC and MD. There were no disagreements in terms of the groupings of codes, but some disagreement with regard to the wording of labels for the groups of codes emerged, which were discussed until resolved. The process of grouping groups of codes was conducted by ROC to develop descriptive sub-themes and themes in a hierarchical tree structure. This descriptive map and individual understandings of the data were then discussed between reviewers to develop a final descriptive thematic map of the data, which remained close to the original findings of the included research papers. Finally, the process of developing analytical themes was undertaken in order to specifically address our research questions by ‘going beyond’ the findings of primary studies to generate new understandings. At this stage both reviewers (ROC and MD) reviewed the descriptive themes and sub-themes to infer determinants of mental health, emotional wellbeing and social wellbeing of the participants. Throughout this process it became clear that the concepts of mental health, emotional wellbeing and social wellbeing could not be meaningfully understood separately, due to the shared features and determinants reported by participants. Thus, the reviewers sought to identify the determinants of any or all of these outcomes when producing the analytical thematic map. Based on discussions of their individual interpretations of the data, ROC developed an analytical thematic map to answer the original research question. This analytical thematic map was discussed by ROC and MD and adapted through these discussions. Through these discussions, over-arching themes were also identified; these were often not explicitly mentioned within the participants' accounts or within the descriptions of the themes, but appeared to underpin many of the issues raised by participants.

2.2.4.1 Reflexivity. As stated in the introduction, all authors are aligned with the neurodiversity framework, which takes the view that autism is a natural variation in neurology that occurs within the general population. As such, it is not a 'disorder' and autistic ways of being are equally valid to neurotypical ways of being. We acknowledge that the findings and conclusions of this review would be different if completed by researchers aligned with the medical model, who viewed autism as a 'disorder'. Conducting the qualitative synthesis we did not seek objectivity, but rather using disciplined subjectivity (Sandelowski, 2012), whereby we as reviewers endeavoured to be consistently aware of our own viewpoints and biases, in order to represent the views of the participants, while retaining our view that autism is part of neurodiversity and not a 'disorder'. For example, when participants described their lack of skill in an area or discussed self-blame for challenges they experienced, we discussed that this could be described as autistic 'deficits' (within the medical model) or the result of an expectation in the neurotypical world (within a social model).

2.3 Results

2.3.1 Overview of studies

The reviewers identified 728 unique records, with a total of 41 studies being included in the current review. Within these studies a total of 690 autistic girls and women were participants (252 of these were from online forums within one study; Nagib et al., 2020) ranging from 13 to 70+ years old. Excluding the study by Nagib and colleagues (2020), on average the female sample size of studies included in this review was approximately 11 (m = 10.95). Thirty-two studies utilised interviews to collect data, while 5 used qualitative surveys, 3 conducted focus groups and 1 study analysed online blogs. Studies that used surveys typically had larger sample sizes, though often the data available to extract was not as rich as interview or focus group data. The study that analysed online blogs had the largest sample size (n = 252), but contained a relatively small amount of relevant data to extract.

Of the studies included in this review, 33 discussed experiences that impacted emotional wellbeing, 36 discussed social wellbeing and 23 included discussion of factors related to mental health, as per the definitions employed by this review. The UK accounted for the largest number of studies included in this review (n = 18), while 8 were conducted in Australia and 9 in the USA. The primary study topics of the included studies were variable, including topics such as: general experiences and needs (n = 5), university experiences (n = 5) and camouflaging/ masking (n = 4). During the full-text screening process 22 studies were excluded due to an insufficient sample of female participants and 19 studies were excluded because participant gender was not identifiable in the findings (other reasons for exclusion are reported in Figure 1).

The quality of the studies was generally good, with 26 receiving a high-quality rating (++) and the remaining 15 receiving a medium-quality rating (+). 9 studies were clearly neurodiversity affirmative (++), 14 studies were somewhat neurodiversity affirmative (+) and 18 were clearly or predominantly based on a deficit-based model (-). Table 3 provides an overview of the studies included in this review, including sample size, age range, mean age, study topic, data collection method, quality rating and review topics discussed (i.e. emotional wellbeing, social wellbeing and mental health).

Table 3

Overview of studies included in the systematic review

First author	Year	Country	N (f/m)	Mean age (range)	Main topic	Data collection	QA	EWB	SWB	MH
Anderson	2020	Australia	7/ 2	Unknown (18 – 70+)	University experiences	Interview	++	▯	▯	▯
Baldwin	2016	Australia	82/ 0	32.7 (18 – 64)	Experiences and needs	Survey	++	▯	▯	▯
Berkovits	2020	USA	5/ 33	15.1 (all 15)	Perception of autism diagnosis	Interview	++		▯	
Bernardin	2021	USA	5/ 5	15.7 (13 – 18)	Camouflaging	Interview	++	▯	▯	
Cheak-Zamora	2019	USA	7/ 20	19.19 (16 – 25)	Sex and relationship experiences	interview	+	▯	▯	
Cheak-	2018	USA	4/ 7	20.36 (18 – 23)	Transition to adulthood	Interview & photo	++	▯	▯	

Zamora						sharing				
Cook	2021	UK	8/ 6	44.53 (20 – 59*)	Camouflaging	IPR interview	++	✓	✓	✓
Crompton	2020	UK	10/ 2	33.58 (21 – 51)	Within- and cross-neurotype relationships	Intrview	++	✓	✓	✓
Donovan	2020	USA	24/ 0	Adults	Childbirth experiences	Interview	+	✓	✓	✓
Forster	2020	UK	2/ 3	22.6 (22 – 25)	Friendship and mate crime	Interview	+	✓	✓	
Griffith	2011	UK	4/ 7	46.36 (37 – 57)	Support experiences and needs	Interview	+		✓	✓
Halim	2018	Australia	5/ 5	21.8 (15 – 36)	Presentaiton of anxiety	Focus group	++	✓		✓
Hannah	2016	UK	2/ 2	Unknown (18 – 25)	Sex education and sexual awareness	interview	+		✓	✓
Hull	2017	UK	55/ 30	40.71 (18 – 68)	Camouflaging	Survey	++	✓	✓	✓
Jones	2013	UK	3/ 6	(16 – 21)	Perception of autism	Interview	+		✓	
Kanfiszer	2017	UK	7/ 0	(20 – 59)	Lived experiences	Interview	++	✓	✓	✓

Kelly	2018	Ireland	2/ 3	(15 – 17)	Social-communication difficulties	Interview	++	✓	✓	✓
Kinnaird	2019	UK	8/ 2	38.5 (19 – 49)	Impact of autism on eating habits	Interview	++			✓
Krieger	2012	Switzer-land	4/ 2	36.83 (32 – 45)	Success in the workplace	Interview	++	✓	✓	
Leedham	2020	UK	11/ 0	50.82 (43 – 64)	Receiving a diagnosis in adulthood	Interview	++	✓	✓	✓
Lewis	2016	USA	32/ 40	39 (18 – 65)	Receiving a diagnosis in adulthood	Survey	++	✓	✓	
Lewis	2020	USA	28/ 22	27.6 (18 – 57)	Experiences of being in a sexual minority	Survey	++	✓	✓	
Livingston	2019	UK	13/ 37	35.8 (18 – 70)	Compensation strategies	Survey	+		✓	
Mongensen	2015	Austraia	2/ 3	(13 – 19)	Experience of receiving a diagnosis	Interview with flexible mode of	++	✓	✓	

						communication				
Moseley	2020	UK	6/ 0	54.8 (49 – 63)	Experience of menopause	Focus group via chat room	++		✓	✓
Moseley	2020	UK	16/ 0	53.5 (41 – 66)	Experience of menopause	Interviews	++	✓	✓	✓
Murphy	2017	UK	2/ 6	14.38 (13 – 16)	Relationships of adolescents	Interview with PCT	+	✓	✓	
Nagib	2020	Canada	252/ 255	(15 – 60+)	Career exploration and job seeking	Analysis of online forum	+	✓		
Robertson	2018	UK	5/ 5	40 (19 – 60)	Experiences of anxiety	Interview	++	✓	✓	✓
Robledo	2012	USA	3/ 2	35.6 (19 – 57)	Sensory and movement experiences	Interview with artifacts	+	✓	✓	✓
Rogers	2017	Australia	1/ 0	26	Perinatal experiences	Interview	+	✓		✓
Seers	2021	Australia	8/ 0	39.38 (24 – 54)	Women’s experience of being autistic	Interview	+	✓	✓	✓

Smith	2013	UK	3/ 6	33.44 (25 – 49)	Unusual sensory experiences	Interview	+	✓	✓	
Teti	2016	USA	4/ 7	(18 – 23)	Strengths and relilience	Interview with photo-voice	+	✓	✓	✓
Tierney	2016	UK	10/ 0	14.4 (13 – 16)	Social management strategies	Interview	++	✓	✓	✓
Tint	2018	Canada	20/ 0	35.45 (19 – 69)	Service needs and experiences of women	Focus group	+	✓	✓	✓
Van Hees	2015	Belgium	6/ 23	‘Majority’ 18 - 25	Challenges and support needs at university	Interview	++	✓	✓	
Van Hees	2018	Belgium	9/ 25	*M* = 17	Transition to higher education	Interview	++	✓	✓	
Vincent	2019	UK	6/ 15	22.19 (21 – 26)	Transition from higher education	Interview	++	✓		
Vine Foggo	2017	Australia	7/ 0	14.14 (13 – 17)	Social experiences of	Interview or	++	✓	✓	

					adolescent girls	written reponses			
Ward	2018	Australia	2/ 2	28.5 (20 – 35)	Experiences of university	Interview	++	▯	▯

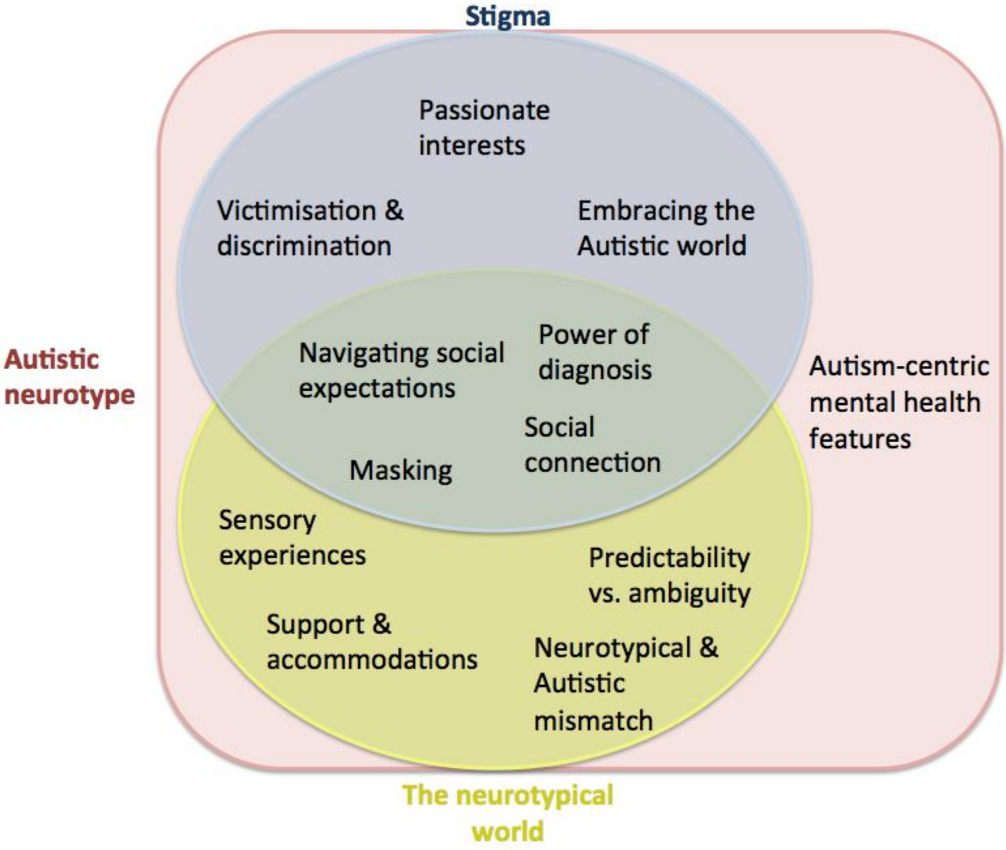
QA = Quality Appraisal; EW = emotional wellbeing; SW = social wellbeing; MH = mental health; PCT = Personal Construct Theory; IPR = interpersonal process recall; NDA = rating of neurodiversity affirmative approach. *approximate, specific not reported in study

2.3.2 Determinants of mental health, emotional wellbeing and social wellbeing

Using thematic synthesis, as described above (Thomas & Harden, 2008), 9 themes, comprising 31 subthemes, were developed from the extracted data, where each theme describes a factor (or multiple factors) that impact upon mental health, emotional wellbeing and/ or social wellbeing of autistic girls and women. All themes and sub-themes fall under one or more of three overarching themes: The Autistic Neurotype, Stigma and The Neurotypical World (see Figure 2. Note that the subthemes within Theme 9: 'Distinctly autistic experiences' are presented separately within this figure, due to the variety of experiences captured within this theme).

Figure 2

Overview of the determinants of mental health, emotional wellbeing and social wellbeing identified in the thematic synthesis.



The ‘Autistic Neurotype’ encompasses the biological and psychological aspects of the autistic neurotype, such as a preference for routine and predictability, having strong interests and particular sensory profiles. ‘The Neurotypical World’ refers to the fact that the world is typically set up in a way that is suitable for neurotypical people. This includes, for example, the physical and sensory environment, the social etiquettes that are in place and how services are structured and delivered. ‘Stigma’ refers to autistic people being regarded as ‘less than’ non-autistic people, which may play out in a variety of ways, such as autistic people experiencing bullying, discrimination or general invalidation of their preferences or experiences. Each theme and sub-theme is discussed detail in Appendix E. See Table 4 for an overview. All themes and sub-themes are somehow connected to having an ‘Autistic Neurotype’. In addition, all except ‘autism-centric features of mental health’ also fall under the over-arching themes of ‘The Neurotypical World’ and/ or ‘Stigma’. That is, it is not an autistic neurotype alone that results in poorer mental health and wellbeing, but rather interaction with various aspects of a neurotypical world and/ or the experience of stigma against autistic people.

Table 4

Overview of thematic synthesis in Phase 1

Theme	**Subtheme**	**No. of papers**	**Illustrative extracted text and quotes**
Neurotypical and autistic mismatch	Neurotypical & autistic mismatch creates barriers	18	*"[autism] is talking to another person through an intercom machine or something and somehow the wires get crossed and they get the wrong message."* (Tierney et al., 2016) *"someone will start reading things into what I have said that I haven't said. Or I won't pick up on what someone else has implied and it just goes to hell, and the drama starts and it is just too much, and I just leave - some people if they don't understand what's going on they will get flustered and be worried that I am not being included, and that will stress me…"* (Halim et al., 2018)
	Neurotypical social environment is	5	*'The physical spaces we go to are extremely challenging. They often want to go to places that are busy or noisy"* (Crompton et al, 2020) *"It feels like in my classroom that I'm surrounded by lions . . . I feel like a mouse and everyone*

	troublesome		*else is like a giant cat or something."* (Tierney et al., 2016)
	Neurotypical peers lack empathy	11	*"But if I am feeling really bad inside, I want people to see the distress signals for what they are. I want people to understand I don't want to hide the urges if I'm feeling really bad. I want people to let me be. I've had all kinds of people who thought they were helping me stop doing things"* (Robledo et al., 2012) *"What are they going to think of me being anxious of such stupid things? And to a normal person it would just be "what is your problem?"… like "what makes you anxious about that? There is no reason to be anxious of that" when really, for someone who all their senses are heightened or not, that is terrifying"* (Robertson et al., 2018)
	Ease with other autistics	6	*"With autistic people, who speak my language…it goes fantastically well most of the time."* (Livingston et al., 2019) More autistic socialising appeared to be associated with increased feelings of ease, authenticity, enjoyment and decreased anxiety, stress, and exhaustion. (Cook et al, 2021)
Masking	Masking is essential in a	12	These comments were interpreted as examples of autistic people feeling that they were in a social minority and felt obliged to conform to the majority way of communicating in social

	neurotypical world		interactions, or face being excluded. *“My neurotypical family can say ‘you are difficult to be around’ if I don’t mask”* (Crompton et al., 2020) *“When I was younger and more obviously odd and strange I was thought of as stupid and also badly physically and mentally bullied. I also lost employment. I want to avoid the bullying mostly. I have even been spat at in the street.”* (Hull et al., 2017)
	Negative emotional impact of masking	10	*“My head will be racing as if I’m interpreting another language. I will be incredibly anxious. It’s like studying for an exam, constantly on edge trying to predict what others will say and do.”* (Hull et al., 2017) *“Yes, it’s very hard and when I came home from my primary school I was very exhausted and tired cos I’d acted so much”* (Tierney et al., 2016)
	Masking supresses true self	6	*“I was married for 15 years and was camouflaging in high gear during that time… My husband would occasionally say to me that he wondered if I was really who I was. I think he would get glimpses of the real me. I didn’t even know who the real me was… The marriage ended in divorce.”* (Hull et al., 2017) *“I feel like I am acting most of the time and when people say that I have a characteristic, I feel*

			like a fraud because I've made that characteristic appear." (Livingston et al., 2019)
	Dropping the mask	6	*"You can let your guard down, you can let your mask down. You don't have to be a certain way with them, because they totally get it"* (Crompton et al., 2020) *"With my really, really close friends I can be more me"* (Murphy et al., 2017)
	Benefits of masking	2	*"With compensation, I have a job in which people respect my work and ask for my help and opinions…I am liked by my colleagues and friends…I haven't lived on the edge, lost and lonely, as I could have. I have been super super lucky.*" (Livingston et al., 2019)
Navigating social expectations	Stress during social interactions	10	*"I do not choose to socialise much, as I find that it is draining. I did not go out and socialise"* (Ward et al., 2018) *"I don't like talking to new people as it makes me nervous. I generally try to avoid talking to new people if I can help it."* (Forster et al., 2020)
	Internalised ableism plays out in social interactions	4	*"despite my awareness, my ability to counteract my poor social skills lags behind. In short, now I know that I am the problem, but I still don't know how to fix myself very well.*" (Livingston et al., 2019) *"I feel awkward and ashamed [when interacting with neurotypical people] . . . I still have a lot*

			of internalised ableism about how I ‘should’ be able to do things that I find difficult.” (Crompton et al., 2020)
	Impact of neurotypical social norms	13	*“I stress about missing body language cues from clients and staff and making a stuff up.”* (Baldwin et al., 2016) The youth discussed at length stress they experienced because they did not understand the “rules” that underlie social etiquette and making mistakes when conversing with peers. (Cheak-Zamora et al., 2020)
Support & accommodations	Type of support and accommodations needed	16	*“I think they’ve got to teach people who are the right people to go with ….more skills on how to find the right sort of partner*.” (Hannah et al., 2016) *“I don’t feel like the daily struggles of adults with Asperger’s are well understood. I fight through (and hide, as best I can) a relentless struggle. I often feel like I just can’t keep going I find that frustrating because there are some areas where it may seem like I am functioning well, when in reality performing in those areas is stressful for me.”* (Baldwin et al., 2016)
	Stress about functioning	4	*“I’m getting really, really anxious and I’m worried that I won’t have the confidence and organisational skills to succeed. Just the thought of going back makes me feel sick. It’s*

	difficulties		*exhausting."* (Ward et al., 2018)
	Barriers to accessing support	7	*"I feel like I am struggling just to get by. I know that I am not receiving the support that I need, but I really don't know of any way to change that. I wish I could feel like I am not just trying to survive, and find the support that I need."* (Baldwin et al., 2016) *"When I was studying, I didn't think I was deserving of special treatment. I thought I should be able to handle it like everyoneelse. So what did I do? When I wrote my exams, I filed myself in with … 400 other people under blinking and blonking florescent lights*." (Tint et al, 2018)
Power of diagnosis	Diagnosis gives power back to the individual	7	Diagnosis created a framework with which to process a coherent self-narrative and no longer pathologise one's thoughts and behaviours. (Seers et al., 2021) Many were kinder to themselves, signifying a progression from self-criticism to self-compassion: "… *to understand where those difficulties and stresses are coming from makes a difference in terms of how I think about myself."* (Leedham et al., 2020)
	Missed and mis-diagnosis	8	*"I was alone with the constant struggling, having no idea why I felt and behaved the way I did. I was told that I was simply too 'dramatic' or 'sensitive'."* (Baldwin et al., 2016) Lily described seeking support within mental health services leading to several diagnoses

			which did not explain her experiences. Failure to find an appropriate understanding or formulation added to the sense of confusion. (Leedham et al., 2020)
	External influences on the perception of the diagnosis	6	Having grown up at a time where neurodevelopmental conditions were heavily stigmatized, some participants felt shock and impact to their self-esteem at diagnosis. (Moseley et al., 2020b) Kim explained that what came with the label, was intense, early intervention directed by a health professional. She experienced this ‘sudden focus’ on her as an effort to change her and frame her identity, in ways that, at that time, she did not understand. (Mongensen et al., 2015)
Victimisation and discrimination	Bullied for being autistic	9	“Gemma’s experiences of victimisation were specifically during adolescence: *‘in secondary school I just got the shit kicked out of me mentally, physically, emotionally, the works, and the teachers joined in’*. She understood her experiences in the context of deviating from the interests of female peers and demonstrating a level of intellect that was not shared by those around her.” (Kanfiszer et al., 2017) *“’Some of them did, some of them didn’t* [know I was autistic]*, but even if they didn’t, they still used to pick on me no matter what. .... ‘cos they knew I was in* [different class in school] *but*

		they would have changed if I was in a wheelchair, then they wouldn't have picked on me. I used to go home crying.'" (Jones et al., 2013)
Social othering and exclusion	17	*"[I feel] empty. Kind of sad about it, like that I can't be open and honest without people treating me less. I don't know how else to word it. It's just, I don't want to be treated like a lesser person."* (Bernardin et al., 2021) "There were recurring reports from all participants that they often felt isolated, leading a largely solitary life in school. They discussed being rejected by their peers, but also times when they segregate themselves for a number of reasons." (Kelly et al., 2018)
Vulnerability to abuse	5	"'It's probably worse, like bullying is generally pretty direct, but this is like… tricking you into thinking that you are a friend. It's more like manipulation and its worse because you're doing it deliberately.'" (Forster et al., 2020) *"'I've been in a bad situation, where to be honest I know now that that person probably was using me. But at the time, I was so head over heels for that person that I didn't really, I didn't really think anything other than "He really likes me"'".* (Hannah et al., 2016)

Social connection	Need for inclusive, supportive and accepting others	19	*“‘… blessed to have such lovely people around … care enough about me not to be bothered by my weird quirks and funny ways … It makes a change after years of bullying and being penalised for being odd.’”* (Leedham et al., 2020) *“’When you’ve got friends who’ve got autism, there’s no point going home crying because everybody’s there for you, you’re there for everybody else. It’s really easier.’”* (Jones et al., 2013)
	Facilitators of social connection	9	*“’Friends often come to me to tell me their story. A lot of my friends say me that they talk to me easily because we can have an open conversation. I am free of bias, in the sense that I just honestly tell them the way things are. I do not beat around the bush, I am not unfriendly, just honest.’”* (Van Hees et al., 2015) *“’Find a club that relates to your special interest and follow through with that because it’s going to be the easiest way to find a suitable social structure within uni.’”* (Anderson et al., 2020)
	Barriers to social	7	*“’It’s hard enough trying to help people understand being on the spectrum, but when you add in a different sexual orientation too, it takes incredibly empathetic people to see beyond the*

	connection		*differences and see the person to form a relationship with them.’”* (Lewis et al., 2020) “Social anxiety and discomfort was referred to by most of the participants with ASD, M1 and F2 reported it to be their “biggest difficulty” when meeting potential partners.” (Hannah et al., 2016)
Embracing the autistic world	Embracing the autistic self	4	“This extended to feeling there was power, strength and pride in diagnosis. Many experienced a changing view of themselves in society, one that was ‘different’ to some, but that difference was in fact neurodiversity and something to celebrate.” (Leedham et al., 2020)
	Embracing the autistic community	5	“*’As lovely as all my neurotypical friends are, I feel I belong there [with autistic people], and I am like everybody else. I have never had that before . . . I feel like I understand people and they understand me.*’” (Crompton et al., 2020) *“‘When you’ve got friends who’ve got autism, there’s no point going home crying because everybody’s there for you, you’re there for everybody else. It’s really easier”’* (Jones et al., 2013)
	Others embracing my	3	*“’I want people to let me be. I’ve had all kinds of people who thought they were helping me stop doing things. I have been endlessly criticized about how different I looked, criticized about*

	autistic self		*all kinds of tiny differences in my behavior. I wish they had accepted some of my behaviors I didn’t have any control over.’”* (Robledo et al., 2012)
Distinctly autistic experiences	Passionate interests	7	“Laura was interested in arts and crafts and shared a picture of a case she sewed for her iPod. She said that her interests – ‘*Do crafts, be an artist, read books, watch TV, play the computer and stuff*’ also made her feel good – ‘free’ and ‘*creative*.’” (Teti et al., 2016) *“‘… when I was at primary school I was very obsessed with windmills and no other kid … shared my interest’*. She poignantly described her experience of feeling different as an *‘invisible glass barrier between me and them’”* (Kanfiszer et l., 2017)
	Predictability vs. ambiguity	14	*“I think in general things that are unpredictable [raise my anxiety] … I am much better with a very nice set plan of what happens.”* (Robertson et al., 2018) *“’I’d say it’s the fear of the unknown because you don’t know what is going to happen, you don’t know if you’re going to succeed or fail. I think that plays a big part of it.’”* (Vincent et al., 2019)
	Sensory experiences	14	*“’Some sounds make me feel really bad in the pit of my stomach. I feel angry and aggressive and out of control; feeling aggressive towards someone who doesn’t deserve it makes me feel*

		guilty. I get very agitated. I may yell at people. My behavior gets out of control. It canruin my mood sometimes for days. The effects of the noise last much longer than the noise itself.'" (Robledo et al., 2012) *''It's very strange because mentally i wanted them to hug me, but physically i couldn't tolerate it. I think that's the same now''' ((Smith et al., 2013)*
Autism-centric features of mental health difficulties	6	*"When we have to think about something that is really difficult or there is too much input, or too much [sic] demands being placed on us on top of sensory input or anxiety, or we experienced executive function issues to a large degree … we enter what's called a 'shutdown', where we feel very tired, very sleepy, and just have to stop for a while, before everything revs up again."* (Halim et al., 2018) *"In individual therapy, participants often described difficulties with emotion identification and their therapists' insensitivity or unawareness of these difficulties"* (Tint et al., 2018)

2.4 Discussion

The present review aimed to identify what factors contribute positively and negatively to the emotional and social wellbeing and mental health of autistic girls and women, by synthesising qualitative self-reports within the available literature. Forty-one studies were identified that met the inclusion criteria. Through a process of thematic synthesis, three over-arching themes, nine main themes, and 31 sub-themes were developed. ‘The Autistic Neurotype’ was the first over-arching theme, which encompassed biological and psychological aspects of the autistic neurotype, such as a preference for routine and predictability, having focussed interests and particular sensory profiles. The synthesis of perspectives presented in this review suggest that the autistic neurotype generally did not have a significant *direct* impact on wellbeing and mental health. Rather, the formulation of the data presented in Figure 2 highlighted that these biological and psychological processes are experienced through the lens of a variety of social factors, which may be summarised under the over-arching themes of ‘The Neurotypical World’ and ‘Stigma’. It is through interaction with these social factors that wellbeing and mental health outcomes were shaped.

Many participants described feeling ‘different’ to their peers due to being neurodivergent in a largely neurotypical world. Being ‘different’ could be experienced as positive, where unique skills and general benefits of diversity are noted, “[…] but that difference was in fact neurodiversity and something to celebrate” (Leedham et al., 2020). However, due to the stigma associated with being ‘different’, it often led to negative outcomes, such as bullying, discrimination and social exclusion (e.g. Bernardin et al., 2021; Jones et al., 2013). Such phenomena are well described by Goffman (1963) in his conceptualisation of stigma. He described stigma as the result of a characteristic, behaviour or social category that is socially discrediting to an individual. That is, stigma lies in the disjuncture between one's actual social identity and the idealised social norm. Depending on whether one's stigmatised identity is known to others or not, one can be classified as 'discredited' or 'discreditable', respectively. Those who are 'discreditable' may engage in impression management, in order to keep their stigmatised status concealed, so as to avoid the negative consequences of stigma in a social context. Similarly, those who are 'discredited' may also engage in impression management to avoid any further stigmatisation. This conceptualisation is easily paralleled to the experiences of autistic people (as previously described by others; Milton, 2013; Pearson & Rose, 2021), whereby many women and girls included in the present review described 'masking' their autistic traits (or 'impression management') in order to avoid bullying, discrimination and rejection (e.g. Hull et al., 2017; Leedham et al., 2020). However, even if masking achieved these aims, the consequences of masking itself were detrimental to wellbeing and mental health, causing anxiety, stress, exhaustion and even meltdowns (e.g. Crompton et al., 2020; Tint et al., 2018), as well as compromising the authenticity of relationships (e.g. Bernardin et al., 2021; Hull et al., 2017). These findings are in line with recent research, which applied the minority stress model to understand autistic adults' mental health and showed that minority stressors, such as discrimination, stigma and masking were predictive of poorer wellbeing and increased distress (Botha & Frost, 2020).

Masking is often conceptualised as a 'female' autistic experience, which some believe partially accounts for girls and women being diagnosed less frequently (Gould & Aston-Smith, 2011; Kreiser & White, 2014; Lai et al., 2020). Indeed, there is some evidence to suggest that women and girls mask more than men and boys (Hull et al., 2020; Wood-Downie et al., 2020), but evidence linking masking to diagnostic timing is currently mixed (Belcher et al., 2021; McQuaid, Raitano Lee, & Wallace, 2022). It should be noted that non-binary people engage in similar levels of masking to autistic women (Hull et al., 2020; Perry et al., 2022). As such, while the present review highlights how stigma and resulting masking impacts autistic girls and women (and the literature also tends to focus on masking in relation to females (Libsack et al., 2021)), it is a phenomenon that occurs to some extent across all genders. It has also been quantitatively linked to mental health difficulties for autistic people of all genders, including increased social anxiety, general anxiety and depressive symptoms, as well as decreased wellbeing (Cook et al., 2021; Hull et al., 2021). Intervention targeted at reducing masking (and thus improving wellbeing and mental health) must be targeted at a community or societal level, as the present review suggests that often the reason autistic people mask, is that it is unsafe not to. As such, ensuring that it is safe for autistic people to unmask must be a priority.

The power of a diagnostic identity (or lack thereof) was described by many of the girls and women in the review. It is well established in the literature that girls and women are less likely to receive a timely diagnosis than their male counterparts (Huang et al., 2021; Petrou et al., 2018), which was also the experience of many of the women included in this review. They described the confusion, self-criticism and overall struggle associated with not having the self-understanding that comes with a diagnosis (e.g. Baldwin et al., 2016; Leedham et al., 2020). Similarly, they described how receiving a diagnosis allowed them to make sense of their experiences, accept themselves and empowered them to make adjustments in their life to accommodate their needs (e.g. Seers et al., 2021). This suggests that supporting self-understanding for newly diagnosed autistic people may be helpful. In line with this, recent research has demonstrated the benefits of post-diagnostic support groups in terms of processing and understanding the diagnosis, as well as connecting with the autistic community (Crompton et al., 2022; Hatton & Lee, 2021). Unfortunately, for some women in this review, stigma played a role in how much they were able to accept and embrace their identity, with many reporting that others' negative reactions to their diagnosis made it difficult to fully accept themselves (e.g. Moseley et al., 2020). This may suggest that while early diagnosis could be very important for autistic girls' and women's mental health and wellbeing, the development of a positive autistic identity and associated self-esteem is somewhat dependent on the reactions of others. Thus, the way autism is assessed, diagnosed and explained to individuals and families should be a positive, affirming and empowering process, in order to best promote wellbeing. It should also be noted that self-identification is increasingly common and accepted within the autistic community, so autistic people may be relying less on the process of formal diagnosis. However, the majority of the included studies recruited participants with formal diagnoses, so we cannot conclude how the process of self-identification may impact mental health or wellbeing, compared to the process of a formal diagnosis.

The present review highlighted that the way the neurotypical world is set up caters to neurotypical needs and preferences, often disregarding the needs and preferences of neurodivergent people. The sensory environment was often described as uncomfortable, distressing or even painful for the autistic girls and women in this review (e.g. Robledo et al., 2012). Adverse reactions to sensory stimuli were reported to occur in response to crowded places (Crompton et al., 2020), bright lights (Tint et al., 2018) or particular acoustics (Krieger et al., 2012). The experience could be so traumatic that it may even lead to 'meltdowns' or 'shutdowns' (e.g. Baldwin et al., 2016) and can create a barrier to social wellbeing, as many social environments are inaccessible to them as a result (Crompton et al., 2020). The neurotypical world also contains social structures and expectations that are not in line with autistic needs and preferences. Discrepancies between autistic and neurotypical communication styles is one such example, whereby participants described miscommunications, misunderstandings and invalidation of the autistic experience, leading to stress, exhaustion, arguments with loved ones and the deterioration of friendships (Crompton et al., 2020; Halim et al., 2018; Leedham et al., 2020; Tierney et al., 2016).

The Double Empathy problem (Milton, 2017) provides a framework to explain this mismatch between autistic people and the neurotypical world by outlining that it is not a deficit present in autistic people, but rather a mutual incomprehension between non-autistic and autistic people that gives rise to the difficulties that autistic people experience. In line with this, a recent study demonstrated that matched neurotype pairs were rated as having higher rapport than mixed neurotype pairs, indicating that autistic people interact naturally and harmoniously with other autistic people, and interaction difficulties only arise within interactions with non-autistic people (Crompton et al., 2020). Similarly, the present review highlighted ease of communication with other autistic people, as well as supportive friendships and groups within the autistic community, which benefited their wellbeing and mental health (e.g. Cook et al., 2021; Halim et al, 2018; Robertson et al., 2018).

2.4.1 Practice implications

The findings of the present review are in line with the social model of disability and mental health. These social models theorise that disabilities or mental illnesses are not a result of a ‘problem’ within the individual, but rather the result of (and/ or exacerbated by) barriers, environments and cultures located outside of the individual (Oliver, 1983; Mulvany, 2000). As per the present review, wellbeing is shaped not by the autistic neurotype, but by the way society creates barriers and stigmatises autistic people, both disabling them and triggering effects on their wellbeing and mental health. Social models suggest that removing barriers and adapting environments are more effective methods of improving the lives of disabled people and preventing mental health difficulties compared to individual interventions (which are often only available to those in a privileged position).

One way to achieve this is through Universal Design, which refers to eliminating barriers by designing environments in an accessible way from the outset, removing the need to provide individual adaptations at a later stage (Steinfeld & Maisel, 2012). In the context of autism, individual or small group ‘interventions’ often consist of social skills training, behaviour modification or interventions targeting desensitisation to sensory stimuli or coping with uncertainty (Gates et al., 2017; Fodstad et al., 2021). Little concrete evidence exists that these interventions are particularly effective (Gates et al., 2017; Riechow et al., 2013), while evidence is emerging that some of these may in fact be harmful to autistic people (Bottema-Beutel et al., 2021), with one study even showing increased rates of PTSD following behaviour modification interventions (Kupferstein, 2018). Instead, universal design may include providing increased certainty via clear visual schedules or designing public spaces to limit any adverse sensory stimuli (Milton et al., 2016). As per the principles of universal design, these adaptations are likely to not only benefit autistic people, but other groups as well, as increased certainty has a positive effect on anxiety levels for the majority of people and removing adverse sensory stimuli would benefit everyone with sensory sensitivities. Perhaps more challenging is designing a social environment where neurodivergent styles of communication and socialising are better understood and embraced. Autism acceptance training and anti-stigma programmes or campaigns have shown some promise with regard to addressing these issues (e.g. Jones, DeBrabander, & Sasson, 2021; Ranson & Byrne, 2014).

2.4.2 Strengths & limitations

The present review made use of existing literature across a range of study topics to improve understanding of autistic female's mental health and wellbeing. To promote the validity and credibility of the review, the review took a systematic approach and involved two (and at times three) researchers determining study eligibility and performing the analysis. In addition, the involvement of MD as an autistic medical professional and researcher is highly valuable, as she was able to provide useful insights on the autistic experience, promoting better understanding of participants' viewpoints.

The present review endeavoured to report on the perspectives of females. However, the review may not have adequately considered the variance in gender identities that exist and how these are represented in the original studies. That is, the original studies largely reported only 'male' and 'female' genders. This is especially problematic given the higher likelihood of autistic people not identifying with the sex they were assigned at birth (Walsh, Krabbendam, Dewinter, & Begeer, 2018) and evidence of participants who were identified as female within the original studies in fact exploring alternative gender identities, *"…because I think like or identify with another gender . . . sometimes, like I don't feel like particularly female…*" (Tierney et al., 2016, p. 80). Thus, while we claim to present a synthesis of female perspectives, participants with other gender identities may be inadvertently included.

Another limitation of the present review is that while our aim is to understand the factors that impact autistic girls and women's wellbeing and mental health, our conclusions can only be based on the literature that is available. Thus, it is impacted the biases that exist around which research projects receive funding, are completed or are successfully published in peer-reviewed journals. For example, the studies within this review were all focussed on an aspect of the autistic (often female) experience, but we assume that autistic mental health is likely also determined by the same factors as non-autistic people, including biological (e.g. genetic), psychological (e.g. cognitive patterns) and social (e.g. poverty) factors. As such, this review is biased due to the studies that exist. In addition, there may be an over-emphasis on some factors, for example autistic people's experience at University, because this is a frequently studied group due to ease of access.

2.4.3 Conclusions

Based on the perspectives of the autistic girls and women included in the present review, experiences of stigma and the challenges associated with living in an unaccommodating neurotypical world play a significant role in mental health and wellbeing of autistic females. Thus, this review indicates that the key to improving the mental health and wellbeing of autistic girls and women lies within communities and society as a whole, rather than addressing 'deficits' associated with being autistic. It should be noted that while the present review focussed on females, it is likely that many of the findings are also applicable to autistic males or autistic people of other genders, as issues related to stigma and the incompatible neurotypical world are not exclusive to females (e.g. Botha & Frost, 2020; Jenkinson et al., 2020). Further research would be necessary to confirm this and perhaps tease out gender differences.

The findings of the present review will not be surprising to many, as similar conclusions have been drawn by some people for many years, particularly autistic people themselves, both in the realm of academia and outside of this (Milton, 2013; The Autistic Advocate, 2018; SoYoureAutistic, 2021). This review supports the view that increased emphasis must be placed on the social determinants of the autistic experience in both research and with regard to supports put in place for autistic people. Furthermore, the studies included in the present review highlight the insight that can be gained by asking autistic people about their experiences and perspectives. As such, future research should focus on gathering the experiences of autistic people (of all genders) to better understand the development of their mental health and wellbeing, in order to identify solutions to the current in autism mental health crisis.

Chapter 3 - A mixed-methods study of the factors that impact the mental health and wellbeing of autistic adults

Abstract

Autistic adults experience more mental health difficulties than non-autistic people, but there is not yet a consensus as to why this is. The present study used a mixed-methods sequential exploratory design to investigate mental health experiences and the factors that contribute to poorer mental health and wellbeing in autistic adults without a co-occurring Intellectual Disability (ID). The qualitative phase consisted semi-structured interviews with 20 autistic adults (aged 19 - 72; 6 cisgender males, 7 cisgender females, 7 trans people). Inductive thematic analysis identified 6 themes with 16 sub-themes, describing factors that impact participants' mental health. Some key factors identified were investigated using standardised measures presented within a survey in the quantitative phase in a sample of 236 autistic adults aged 18 - 70 (*m* = 33.83; 47 cisgender males, 171 cisgender females and 17 trans people). There was substantial agreement between findings, though also some areas of dissonance. High levels of depression and anxiety symptoms and low wellbeing were identified, as well as a range of other mental health conditions and symptoms. Autistic cisgender women reported higher anxiety, while autistic trans people reported higher levels of depression (both compared to autistic men). A wide range of factors were shown to contribute to mental health and wellbeing, including feelings of exclusion and isolation, childhood bullying, autism-related stigma and challenges related to the neurotypical environment. Overall, findings point to the need for community adaptations or interventions to create a more accessible and accepting society, as well as improvements in service provision for autistic adults.

3.1 Introduction

Autism has traditionally been conceptualised through a medical paradigm, which defines autism as a neurodevelopmental disorder characterised by a range of deficits in social-communication, social interaction and restricted, repetitive behaviour (APA, 2013). However, an alternative approach to understanding autism has gained support in recent years, which addresses some of the shortcomings of the medical model; namely the over-focus on deficits, the over-emphasis on the individual as opposed to their social context and the narrowness of the perspective (Pellicano & den Houting, 2022). The neurodiversity paradigm defines autism as a neurotype, which occurs as part of the natural diversity of human neurodevelopment in the population, comparable to biodiversity that is essential within ecosystems (Singer, 1998). Under the neurodiversity paradigm, autism is characterised by differences in social approach, cognitive style and sensory processing compared to the non-autistic population (Kapp, 2020). Specifically, it described that autistic people generally have different verbal and non-verbal communication approaches, as well as a preference for sameness, including a preference for routines and focussed, passionate interests (Kapp, 2020).

Unfortunately, being autistic is associated with an increased rate of mental health difficulties compared to the non-autistic population, including anxiety disorders and depressive disorders (Hollocks at al., 2018; Lai et al., 2019). There is also an increased rate of suicidal ideation, as well as suicidal intent and completion (Cassidy et al., 2018) Zahid & Upthegrove, 2017; Hedley & Uljarević, 2018). Alongside increased levels of mental health difficulties, autistic adults also report poorer psychological wellbeing compared to non-autistic people (Cai et al., 2019; Henderson et al., 2021; Muniandy et al., 2022). The presense of a co-occurring ID may also impact on the mental health and wellbeing for autistic people, whereby those without co-occurring ID experience higher levels of depression and anxiety (Bishop-Fitzpatrick & Rubenstein, 2019; Rai et al., 2018). Due to this difference, as well as other differences between those with and without an ID (such as exposure to particular life circumstances and experiences that are likely to emerge in the present study), the present study will involve a narrower focus, to include only autistic adults without a co-occurring ID.

There is not yet a consensus on why autistic people are at higher risk of mental health difficulties than non-autistic people. As in the non-autistic population, they are likely caused by a complex interplay of factors, including biological, psychological and social influences (Engel, 1977). Indeed, we can assume that many of the same factors are at play for autistic people as in the population as a whole, such as genetic predispositions to mental health difficulties (biological), self-esteem (psychological) and poverty (social; Carr & McNulty, 2016). But what factors put autistic people at a higher risk? An association between autistic traits and symptoms of mental health conditions has been shown quite consistently in both in the autistic and non-autistic population (e.g. Albantakis et al., 2020; Sampson et al., 2021), but the mechanisms within this relationship are not yet clear. Much research has focussed on biological and psychological traits associated with being autistic that may result in poorer mental health. For instance, heightened or reduced sensory responses and ‘intolerance of uncertainty’ [a heightened or maladaptive response to uncertain situations; Stark et al., 2021] have been linked with anxiety outcomes in adults (Hwang et al., 2019). Though more nuanced views and debate around perceived ‘intolerance of uncertainty’ suggest that it is differences in predictive processing that give rise to uncertainty and anxiety in neurotypical environments (Stark et al., 2021; Bervoets, Milton, & Van de

Cruys, 2021). Furthermore, alexithymia [a difficulty experiencing, identifying and expressing emotions], which occurs in approximately 50% of autistic people (Kinnaird, Stewart, & Tchanturia, 2019), has been associated with depression, anxiety and suicidality in autistic adults (Costa et al., 2020; Morie et al., 2019). Furthermore, autistic people often experience co-occurring conditions, such as ADHD and epilepsy, which have been shown to impact the mental health of autistic adults (Smith & Matson, 2010; Pehlivanidis et al., 2020). What many of these biological and psychological explanations may be missing is consideration of the wider social context of autistic people, and how this may play a role in the development of mental health difficulties. Indeed, these theories are generally more aligned with the medical paradigm, often considered to be too narrow and individualistic in its approach to autism (Pellicano & den Houting, 2022).

The neurodiversity paradigm encourages autism science to consider the social environment when developing our understanding of the autistic experience. In line with this, evidence of the social factors that contribute to autistic people’s mental health has developed in recent years. Experiencing adverse life events, such as physical and sexual assault or socio-economic disadvantage were found to predict mental health outcomes for autistic people (Griffiths et al., 2019; Rumball et al., 2021), as the do in the population as a whole (Hillberg et al., 2011; Freeman et al., 2016). The impact of stigma and discrimination has also been examined in several ways. Autistic people’s perception of the stigma towards them (and autistic people generally) was shown to be related to poorer mental wellbeing (Perry et al., 2022), while internalised stigma was predictive of psychological distress (Botha & Frost, 2020). On the other hand, the concept of autism acceptance, which refers to feeling accepted or appreciated by others as an autistic person, has been studied by Cage and colleagues (2018), who similarly showed that acceptance by others was related to fewer symptoms of depression. Moreover, self-acceptance was related to decreased levels of depression (Cage et al., 2018), which mirrors other research showing that having a positive view of autism and one's own autistic identity is related to increased wellbeing, lower depression and better self-esteem (Cooper et al., 2021; Maitland et al., 2021). However, in the absence of autism acceptance and the presence of stigma in society (Cage et al., 2018; Jones et al., 2021), autistic adults describe protecting themselves by engaging in masking (also known as 'camouflaging'; Hull et al., 2017), which is the (either conscious or unconscious) concealment of autistic traits to avoid the negative consequences associated with a stigmatised identity, e.g. victimisation and discrimination (Pearson & Rose, 2021). Stigma and masking appear to have unique and/ or interconnected impacts on the mental health of autistic adults (Botha & Frost, 2020; Cook et al., 2021; Perry et al., 2022).

Gender influences autistic people's likelihood of having mental health difficulties, whereby autistic women are at a further increased risk of depression, bipolar disorder and suicidality compared to autistic men (Hirvikoski et al., 2019; Lai et al., 2019; Varcin et al., 2021), while autistic men are more likely to develop schizophrenia (Varcin et al., 2021). Autistic trans people's risk of depression and anxiety may be higher again (Murphy al., 2020), which is true also for non-autistic trans people (Budge et al., 2013). It is crucial we understand why all autistic people have poorer mental health compared to non-autistic counterparts and understanding the particular influence of gender will help to identify particular issues and biopsychosocial risk factors in the autistic population.

Historically it was believed that significantly more men were autistic than women, with gender ratio of 4:1 cited when including people both with and without co-occurring intellectual disabilities (ID; Rutter, 1978) and 9:1 when only considering those without an ID (Wing, 1981). Theories such as the ‘extreme male brain’ theory, which suggested that autistic traits were an ‘extreme’ version of common sex-differences related to empathising (strengths in interpreting human behaviour and emotions) and systemising (strengths in logic, attention to detail and reasoning; Baron-Cohen, 2002) supported and perpetuated the idea that autism is a predominantly ‘male’ condition. However, recent studies into the gender ratio in autism suggest that the gender ratio is approximately 3:1 in children (Loomes et al., 2017) and that this decreases further with age (Posserud et al., 2021), strongly suggesting that diagnostic biases play a significant role in the apparent gender discrepancy. The diagnostic biases and resulting late diagnoses may be one reason that autistic females often report higher levels of mental health difficulties than autistic men, as girls and women who are not identified as autistic in childhood have described the challenges they face as a result of lacking this essential information about their identity, as well as missing out on the support that could have been provided (Baldwin et al., 2016; Leedham et al., 2020). In keeping with this, some research has suggested that receiving a diagnosis earlier in life is associated with better wellbeing outcomes in adulthood (Oredipe et al., 2022). Girls and women also tend to report increased levels of masking compared to men (Hull et al., 2020; Wood-Downie et al., 2020), which is known to be associated with a multitude of negative mental health outcomes, supported by both qualitative and quantitative research (e.g. Cook et al., 2021; Hull et al., 2021; Cassidy et al., 2018). Considering the traditional focus on cisgender males in autism research as well as the potential impact of these social factors, which are associated with being female, the role of gender must be taken into account in mental health research.

When examining the role of gender in mental health outcomes, we must consider the wide range of genders, rather than just binary sex categories. This may be especially important for autistic people, as they are more likely to be trans than non-autistic people (van der Miesen et al., 2018; Walsh et al., 2018). As stated previously, both autistic and non-autistic trans people more likely to experience mental health difficulties than cisgender people (Murphy et al., 2020; Budge et al., 2013). Like autistic cisgender women, autistic trans people also report issues around others accepting their autistic identity due to the stereotyped view of autism as a 'male' condition (Strang et al., 2018), though to our knowledge no studies have examined if diagnostic timing is impacted in this group. Experiences of harassment, discrimination and social isolation due to being trans has been shown to impact the mental health of both autistic and non-autistic trans people (Cooper et al., 2020; Valentine & Shipherd, 2018), but the difficulties seem to be exacerbated for autistic trans people, due to having two marginalised identities (Cooper et al., 2020). Thus, the importance of understanding the social influences on mental health is also crucially important for autistic people of all genders.

Empirical studies gathering the perspectives of autistic adults on their own experiences have accumulated in recent years, with a wide variety of focuses, many of which overlap with their mental health, such as sensory experiences (e.g. Robertson & Simmons, 2015), masking (e.g. Hull et al., 2017) and trauma (e.g. Kerns et al., 2022). However, to the best of our knowledge a study directly examining autistic adults' perspectives on the factors that influenced their mental health throughout life does not yet exist. In order to prevent mental health difficulties and treat them when they do occur, we must accurately understand why such difficulties develop. Using methodology that places the lived experiences of autistic people at the centre is considered to be critically important to achieving this aim (van Schalkwyk & Dewinter, 2020; Crane et al., 2021).

3.1.1 Present study

The rate of mental health conditions in the autistic population is believed to be significantly higher than the population as a whole and this is documented in research conducted in numerous countries around the world (Lai et al., 2019; Hollocks et al., 2019). However, there are currently no studies examining the mental health and wellbeing of a sample of autistic adults in Ireland. Therefore, the first aim of the present study is to understand the experiences of and levels of mental health difficulties and metal wellbeing in a sample of autistic adults of Ireland. Within this aim, the role of gender will be examined, specifically exploring whether levels of mental health and wellbeing symptoms differ between cisgender men, cisgender women and trans people.

Moreover, the reasons for the increased mental health difficulties in the autistic population are not yet well established in the scientific literature. In order to prevent and treat mental health difficulties in autistic people, as well as promote their mental wellbeing, it is important to understand the factors that contribute to the difficulties they experience. Thus, the second aim of the present study is to explore and understand the factors that impact the mental health and wellbeing of autistic adults (without a co-occurring ID), from the perspective of autistic adults themselves.

In order to ensure that this research is conducted in line with the priorities, preferences and values of autistic people, it will take a ‘participatory research’ approach, which involves creating partnerships with autistic individuals and acknowledging their role as ‘autism experts’ (Fletcher-Watson et al., 2019; Gillespie-Lynch et al., 2017).

Two over-arching research questions that are addressed in the present study are as follows:

1. What are the experiences of and levels of mental health difficulties and mental wellbeing in a mixed-gender convenience sample of autistic adults living in Ireland? Do the levels of mental health symptoms and mental wellbeing vary depending on gender?
2. What factors contribute to the mental health and wellbeing of autistic adults (without a co-occurring ID) in Ireland?

As will be demonstrated, the qualitative phase of the present study identified several self-reported determinants of mental health, which were then examined within the quantitative phase of the present study. As such, within research question 2 (as above), the following identified factors will be examined quantitatively with regard to their relationship with mental health and wellbeing:

- Childhood bullying
- Sense of belonging/ inclusion
- Autism stigma
- Positive autistic identity
- Age at diagnosis/ self-identification

3.2 Methods

3.2.1 Community participation

In line with the British Psychological Society (BPS) guide for producing doctoral research with impact and recommendations from the autistic community, key stakeholders were consulted throughout the research (BPS, 2018; Fletcher-Watson et al., 2019). The present study was conducted as part of a collaboration between the first author and Ireland's national autism charity, AsIAm. The initial conception of this study was developed by ROC through consultation with KG. This was further developed through conversations with (autistic) staff members of the charity partner. Next, a 'consultation panel' of 9 autistic adults was created to advise on every stage of the research process. In order to create a consultation panel, ROC and an AsIAm staff member developed a role description for the panel members and guidelines for decision-making that would inform how we collaborated with the consultation panel to develop the study. The panel members were asked to give approximately 6 – 10 hours of their time by way of attending meetings, participating in workshops, reading proposals and providing written feedback at various stages of the research process.

As I Am advertised the role of consultation panel member and collected some basic demographic data from applicants. A panel of 8 people was initially created by screening the applicants based on the demographic data provided to ensure that a representative group was formed, in terms of age, gender, ethnicity and sexuality. A ninth member of the panel was added when an individual over 65 expressed interest (a demographic that was missing from the initial group of applicants). Each member of the consultation panel received a €50 voucher for their contribution to the research.

The consultation panel met with the researchers on five occasions over an 18-month period. These meetings took place via Zoom in order to comply with government restrictions during the COVID-19 pandemic. The first 3 sessions focussed on developing the research proposal. During these sessions the panel members advised on how to make the participation process more pleasant for participants, what accommodations we could provide and how we may reach more marginalised members of the autistic community (e.g. those from the Travelling Community or those aged over 65). Decisions were made using the ‘five finger decision method’ as described by Nicolaidis and colleagues (2011; see Appendix F). Based on these discussions, a research proposal was developed, on which panel members subsequently had the opportunity to provide written feedback via email. At this stage three panel members responded to give their full approval of the proposal, the others did not provide any feedback. Adaptations were made to the research plan after Phase 1 of the study (i.e. some changes to the questionnaires used in Phase 2), but due to time constraints the consultation panel were not involved in this process.

After the data was collected, the consultation panel met with the researchers on two further occasions, participating in workshops that took place via Zoom. At these workshops the panel members were provided with excerpts from the interviews and the analysis completed by ROC. In small breakout groups the panel members had discussions focussed around some key talking points around the interpretation and implications of the findings (see Appendix G). Notes taken by the panel members and researchers during these workshops contributed to the interpretation and recommendations presented in the present study. Specifically, while the structure of the hierarchical thematic map was not altered, descriptions of the themes were enhanced by panel members’ insights and interpretations. In addition, recommendations suggested by the panel members are included in the discussion section.

In order to share the findings of the present study with the autistic community, a webinar aimed at autistic adults and family members of autistic people will be organised. Panel members will also be invited to share their experience of the project within this webinar. In addition, an infographic will be produced in collaboration with AsIAm to share the findings of the present study more widely among the autistic and autism community.

3.2.2 Overall study design

The present study employed a mixed-methods approach, using a sequential exploratory design. The first phase of the present study consisted of semi-structured interviews with autistic adults who have experience of mental health difficulties. These interviews focussed on gathering the individuals' perspectives on what factors, events or experiences had impacted their mental health. In order to formulate a list factors and associated hypotheses to explore further in Phase 2, ROC engaged in preliminary analysis of the interviews, in consultation with KG and another senior researcher (GC). First, all interviews were read and re-read by ROC to begin generating understandings of common topics. Next, ROC re-read each interview carefully again, taking note of the topics that were discussed in each interview. This resulted in a list of topics, along with their frequency. This was examined by ROC to identify common factors discussed by participants and develop associated hypotheses. This draft list of factors and hypotheses to explore in Phase 2 was discussed with KG and GC, who provided feedback and facilitated reflection on the draft list. The list was then reviewed and adapted by ROC before KG and GC reviewed and approved this final version. These identified factors and associated hypotheses were then investigated quantitatively in Phase 2 of this study to determine whether the link between these factors and mental health is evident in a larger group of autistic adults.

Quantitative data with regard to levels of wellbeing, anxiety and depression were also gathered in Phase 2, acting as dependent variables and allowing us to assess the levels of mental health symptoms and wellbeing in this sample of autistic adults living in Ireland.

Ethical approval for this study was provided by the University College Dublin’s Research Ethics Committee (see Appendix H). All participants provided written informed consent for participation.

3.2.3 Phase 1

3.2.3.1 General procedure. Purposive sampling was used to recruit participants for Phase 1 of the study, whereby participants who met specific criteria were eligible to take part in the interviews. These criteria were (1) being autistic (formally diagnosed or self-identified), (2) being 18 or over, (3) living in Ireland, (4) not having a diagnosis of a co-occurring intellectual disability, and (5) having experience of mental health difficulties. The study was advertised via the social media channels of the charity partner, as well as more generally. Potential participants who met the above criteria were invited to express their interest by completing a short survey, which included the information sheet (see Appendix I), consent form (see Appendix J) and a demographic questionnaire. Potential participants also specified their preferred interview type and provided their contact information. Demographic information of the potential participants was reviewed regularly by ROC to ensure that a diverse sample was achieved in terms of gender, age, sexuality and ethnicity. Where certain groups were missing from the pool of potential participants, these groups were targeted specifically via advertising the study in particular social media groups or contacting other relevant organisations. All potential participants who met the inclusion criteria were contacted via email to arrange their interview. Participants were offered the choice of an oral interview (via Zoom) or a written interview (via Zoom chat function or via an online survey that participants could complete in their own time). Participants could also use a combination of oral and written interview via Zoom. Participants who took part via online survey were emailed with any follow up questions and asked to reply within 2 weeks.

All interviews were conducted in a sensitive manner. Participants were provided with interview material in advance, including the interview schedule and information about the interviewer and broader research team, along with photos. The interviewer explained to participants that they could take break at any time during the interview and could decline to answer any questions they did not feel comfortable answering. Participants had the option at the beginning of the interview to decide on a non-verbal signal to indicate to the interviewer that the interview should be stopped or paused. In addition, the interviewer used clinical judgement throughout and offered the participants breaks or the option to decline to answer questions when they appeared uncomfortable.

3.2.3.2 Participants. Twenty autistic adults took part in Phase 1 of the present study. They identified as 6 cisgender men, 1 transgender man, 7 cisgender women, 1 transgender woman, 4 non-binary people and one agender person, aged between 19 and 72 (median age = 26). Sixteen participants had a formal autism diagnosis and 4 were self-identified as autistic. 14 participants were diagnosed/ identified in adulthood, while the remaining 6 participants were diagnosed before the age of 18. All but 2 participants reported co-occurring conditions, with ADHD (n = 9) depression (n = 15) and anxiety (n = 13) reported most frequently. See Table 5 for further demographic information[2].

Sixteen participants took part in oral interviews via Zoom, 3 participants completed the interview via online survey and 1 participant completed a partially oral and partially written interview via Zoom. Oral interviews lasted between 32 and 85 minutes. The three participants who completed the interview via online survey did not respond to follow-up questions via email. Interviews conducted via spoken communication yielded on average 68.56 codes, while interviews conducted in written format yielded on average 42 codes (the mixed interview yielded 61 codes). When tested with an independent samples t-test the difference in the number of codes between spoken and written interviews was not statistically significant. However, the low power due to the small sample of written interviews may have influenced this.

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[2] Additional demographic data was collected, but is not reported here to protect the anonymity of participants.

Table 5

Demographic information of participants in Phase 1

Ptp. No.	Gender	Age	Ethnicity	Diagnosis type	Age at diag.	Sexuality	Interview type
1	Male	57	White Irish	Formal	40	Heterosexual	Speaking
2	Male	36	White Irish	Formal	36	Heterosexual	Speaking
3	Male	26	White Irish	Formal	23	Heterosexual	Speaking
4	Female	42	White (other)	Formal	41	Heterosexual	Speaking
5	Non-binary	19	White Irish	Formal	18	Homosexual	Speaking
6	Male	39	White Irish	Formal	28	Homosexual	Speaking
7	Female	21	White Irish	Formal	17	Homosexual	Speaking
8	Agender	19	White Irish	Formal	11	Asexual	Mixed
9	Non-binary	35	White (other)	Self	Missing	Demi-sexual Panromantic	Speaking
10	Female	27	White Irish	Formal	15	Homosexual	Speaking
11	Male	20	White Irish	Formal	3	Heterosexual	Speaking
12	Male	23	White Irish	Formal	12	Heterosexual	Speaking
13	Trans female	24	White Irish	Formal	22	Pansexual	Speaking
14	Female	24	White Irish	Formal	6	Heterosexual	Speaking
15	Female	72	White Irish	Formal	70	Heterosexual	Speaking

16	Female	31	White Irish	Self	30	Heterosexual	Speaking
17	Non-binary	50	White Irish	Formal	47	Heterosexual	Speaking
18	Trans male	25	White Irish	Self	25	Bisexual, grey-ace	Written
19	Non-binary	23	White Irish	Formal	16	Bisexual	Written
20	Female	missing	White (other)	Self	38	Heterosexual	Written

3.2.3.3 Measures

Demographic information. Participants completed an online survey to collect relevant demographic information. See Appendix K.

Semi-structured interviews. The semi-structured interview schedule was developed by ROC, with the input of co-researchers. First ROC created a draft interview schedule by mapping research questions onto interview topics and potential questions that would elicit a description of this topic. Questions were generated based on an atheoretical perspective and the assumption that autistic people are experts in both themselves and the autistic experience (Gillsepie-Lynch et al., 2017). Thus, the questions were designed to ask participants in a direct and open-ended way about the factors that influenced their mental health throughout life, and follow-up questions were similarly designed to follow the participants' lead with regard to significant events and influences. The initial draft version of the interview schedule was reviewed by KG, as well as the consultation panel. The feedback was incorporated, by changing and editing some questions (e.g. to make the questions more direct and clear). Next, four pilot interviews were conducted; 2 with members of the consultation panel and 2 with staff members from AsIAm, in order to fine-tune the interview schedule and process. Based on these pilot interviews, minor adaptations were made to the interview schedule to produce the final version.

Within the interviews participants were asked open-ended questions about their experiences of mental health difficulties and what factors, events or experiences have impacted (negatively or positively) on their mental health. Questions were sufficiently broad and open-ended so as not to limit or bias participant responses (e.g. “What things in life have contributed to your mental health difficulties?”). Follow up questions were asked to gain more information or insight into participants experiences and how they impacted on their mental health (e.g. “Can you tell me more about that?” or “How was it exactly that [factor] impacted your mental health?”). Within these interviews participants were also asked about their experiences of seeking support for their mental health, but these findings are not reported within the present study. See Appendix L for full interview schedule.

3.2.3.4 Analysis. A critical realist approach was taken when developing an understanding of the data. That is, it is not assumed that the data can produce a clear image of what is occurring, but rather the data show how the situation is perceived by the participants. Thus, further interpretation is needed to understand the potential underlying factors that are present, which the participant may be unaware of (Willig, 2013). An inductive approach was taken throughout the analysis, whereby the codes and themes were driven by the data. Latent themes were developed, which attempt to identify underlying ideas and phenomena that shape the content of the data. The aim of the analysis is to give a rich description of the data overall, to give an overall sense of what factors contribute to autistic people’s mental health, which is appropriate for this exploratory stage of the research.

All oral interviews were audio recorded and transcribed verbatim into word documents. Written responses to interview questions were copied into word documents to create transcripts. All interviews were anonymised by removing personal information that could identify the individual, such as names, places and services. The resulting transcripts were analysed by ROC using thematic analysis, following the six-phase approach outline by Braun and Clarke (2006), conducted within a critical realist framework. Analysis was also informed by later advancements Braun and Clarke’s work (e.g. Braun & Clarke, 2013; 2019). First, ROC familiarised herself with the data, by reading and re-reading the data and developing some initial thoughts and ideas around possible codes and themes. For the remainder of the analysis, NVivo (version 12) was used. ROC engaged in line-by-line coding of the data, assigning a code to relevant data and assigning multiple codes where needed. The coding process was inductive, meaning codes were data-driven and not theory-driven. Next, the resulting list of codes was sorted into potential themes and sub-themes to develop an initial thematic map. Then, these potential themes and sub-themes were reviewed and adapted, by (1) reviewing the coded data to check if a consistent pattern is evident and whether this supports the theme or sub-theme identified, and (2) reviewing the entire dataset to consider how well the identified themes fit with the data. As a result of these two processes, themes were re-worked and refined to produce the final set of themes and sub-themes. These were also visually represented, so as to consider the links between themes and between sub-themes. Finally, each theme and sub-theme was named, based on its essence and importance within the analysis and interpretation of the dataset. In addition, a detailed description of each theme and sub-theme to tell its individual ‘story’, as well as how it sits within the overall ‘story’ of the analysis.

Reflexivity. In advance of the qualitative analysis process, I reflected on my role within the research and how my beliefs and experiences may impact the research process. I acknowledge firstly that I am not autistic and therefore my analysis and interpretation of the data will be the perspective of an ‘outsider’. I anticipated (based on my reading of the existing literature) that participants would likely discuss how neurotypical people have contributed to their mental health difficulties. As a neurotypical person, I must ensure that defensiveness does not impact my analysis of the data. At the same time, I do consider myself an ally to the autistic community and to be aligned with a neurodiversity framework (as opposed to the medical model) and the theories on which I base my understanding of autism are mostly theories developed by autistic people. I am very determined not to perpetuate any deficit-focussed narratives of autism, thus causing harm to the autistic community. As such, I must also be aware of this wariness, which may prevent me from acknowledging findings that are contrary to my beliefs and the narrative of the autistic experience that I would like to portray.

In order to limit bias resulting from my own position, I kept a reflective diary throughout the analysis process. In this diary I noted thoughts and feeling that emerged throughout the analysis process. I often reflected on different ways to interpret particular statements or groups of statements from participants, depending on whether these data are approached from a neurodiversity or medical model of thinking. Rather than objectivity, I sought disciplined subjectivity (Sandelowski, 2012), whereby I acknowledged how the medical model may interpret the data, but chose to interpret it from a neurodiversity lens.

3.2.4 Phase 2

3.2.4.1 General procedure. Phase 2 of the present study consisted of an online survey aimed at quantitatively examining key factors identified in Phase 1. Convenience sampling was used to recruit participants via the social media channels of the charity partner (as well as more generally). Autistic adults (without a co-occurring ID) living in Ireland were invited to take part in the online survey about mental health and wellbeing. Potential participants could follow a link to the information sheet (see Appendix M) and consent form (see Appendix N), which subsequently led them to the online survey. The survey was made up of the demographic questionnaire (as per Appendix K) and multiple validated questionnaires measuring aspects of mental health, wellbeing and factors hypothesised to be linked to mental health and wellbeing (see Appendix O). At the beginning of the survey participants were asked to select their preferred autism terminology to customise the survey (i.e. ‘autistic person’/ ‘person with autism’/ ‘person on the spectrum’). Their preferred terminology was then presented to them in subsequent items, where relevant. Due to most participants preferring identity-first terminology (50.2%) or having no preference (23.7%), identity-first language is used throughout this paper.

3.2.4.2 Participants. In total 236 autistic adults aged 18 – 70 (m = 33.83, SD = 11.15) took part in this study, these were 172 women (including one trans woman), 50 men (including 3 trans men), 11 non-binary people, one agender person and one person who described themselves as ‘female/ agender’ (one participant selected ‘prefer not to say’). One hundred and eighty participants had a formal diagnosis of autism, while 56 were self-identified. Fifty-three were diagnosed in childhood (aged 3 – 17) and 174 were diagnosed in adulthood. Participants did not have co-occurring intellectual disabilities, but 159 participants reported having other co-occurring conditions, including both other forms of neurodivergence and mental health conditions. A further 42 participants were unsure if they have co-occurring conditions. See Table 6 for further participant demographic information.

For the purposes of analysis, gender was separated into 3 categories; cisgender male, cisgender female and trans people (this includes all participants who do not identify with the gender they were assigned at birth). While the participants within this trans group have unique experiences depending on their specific gender identity, they share the experience of not identifying with the gender they were assigned at birth. Their Mean scores, Standard Deviations and score ranges across variables are comparable to the other genders included. Thus, it was deemed appropriate (as well as socially meaningful) to consider them a homogenous group for the within the analysis.

Table 6

Demographic information of participants in Phase 2

Characteristics	**N**	**%**		
Gender (n = 235)				
Men (of which trans)	50 (3)	21.2		
Women (of which trans)	172 (1)	72.9		
Non-binary	11	4.7		
Agender	1	.4		
Female/ agender	1	.4		
	N (%)			
	Cis male	**Cis female**	**Trans**	**Total**
Age (n = 208)				
18 - 25	12 (26)	38 (22)	9 (53)	60 (29)
26 - 35	10 (21)	48 (28)	4 (24)	62 (30)
36 - 45	12 (26)	41 (24)	3 (18)	56 (27)
46 - 55	3 (6)	16 (9)	1 (6)	20 (10)
56+	4 (9)	6 (4)	0 (0)	10 (5)
Diagnosis (n = 236)				
Formal diagnosis	40 (85)	123 (72)	16 (94)	180 (76)
Self-identified	7 (15)	48 (28)	1 (6)	56 (24)
Age at diagnosis (n = 227)				
Under 18	19 (40)	27 (16)	6 (35)	53 (23)

18+	27 (57)	136 (80)	11 (65)	174 (77)
Sexuality (n = 226)				
Heterosexual	35 (75)	99 (58)	1 (6)	135 (58)
Homosexual	4 (9)	12 (7)	6 (35)	22 (10)
Bisexual	4 (9)	30 (18)	7 (41)	41 (18)
Other*	2 (4)	18 (11)	2 (12)	23 (10)
Ethnicity (n = 236)				
White Irish	45 (96)	147 (86)	15 (88)	208 (88)
White (other)	2 (4)	22 (13)	1 (6)	25 (11)
Other	0 (0)	2 (1)	1 (6)	3 (1)
Employment status (n = 235)				
Full time	17 (36)	44 (26)	5 (29)	67 (29)
Part time	3 (6)	29 (17)	0 (0)	32 (14)
Self-employed	2 (4)	14 (8)	1 (6)	17 (7)
Student	7 (15)	29 (17)	3 (18)	39 (17)
Not working	13 (28)	37 (22)	7 (41)	57 (24)
Retired	2 (4)	2 (1)	0 (0)	4 (2)
Other	3 (6)	15 (9)	1 (6)	19 (8)
Co-occurring conditions (n = 236)				
ADHD				
Formal diagnosis	15 (32)	17 (10)	3 (18)	36 (15)
Self-identified	5 (11)	49 (29)	3 (18)	57 (24)
Dyslexia				
Formal diagnosis	6 (13)	17 (10)	2 (12)	26 (11)
Self-identified	5 (11)	12 (7)	1 (6)	18 (8)

DLD				
Formal diagnosis	1 (2)	4 (2)	1 (6)	6 (3)
Self-identified	2 (4)	3 (2)	0 (0)	5 (2)
DCD				
Formal diagnosis	4 (9)	17 (10)	2 (12)	24 (10)
Self-identified	3 (6)	21 (12)	2 (12)	26 (11)
Depressive disorder				
Formal diagnosis	15 (32)	77 (45)	9 (53)	101 (43)
Self-identified	8 (17)	23 (14)	3 (18)	35 (15)
Anxiety Disorder				
Formal diagnosis	19 (40)	92 (54)	10 (59)	122 (52)
Self-identified	10 (21)	36 (21)	1 (6)	47 (20)
OCD				
Formal diagnosis	6 (13)	21 (12)	6 (13)	27 (11)
Self-identified	2 (4)	21 (12)	2 (4)	25 (11)
PTSD				
Formal diagnosis	6 (13)	21 (12)	3 (18)	30 (13)
Self-identified	3 (6)	31 (18)	4 (35)	38 (16)

*Participants identified with a range of other sexualities, including asexual, queer, pansexual and demisexual.

3.2.4.3 Measures. All of the following were included in an online survey, distributed via Qualtrics. See Appendix K for demographic survey and Appendix O for other measures.

Demographic information. Comprehensive background information about participants was gathered. This included age, gender, ethnicity, sexuality, level of education, employment status, living situation, age at diagnosis, communication mode preferences, co-occurring conditions, and history of accessing support for mental health difficulties.

Ritvo autism and Asperger Diagnostic Scale (RAADS-14). Participants completed the RAADS-14 (Eriksson et al., 2013), which measures autistic characteristics, to create the Autistic Traits variable. The scale contains 14 items relating to typical autistic traits, such as experiences of social interactions (e.g. “How to make friends and socialise is a mystery to me”), sensory stimulation (e.g. “When I feel overwhelmed by my senses, I have to isolate to shut them down”) and routine (e.g. “I get extremely upset when the way I like to do things is suddenly changed”). Participants rate each item on a 4-point Likert scale (0 = never true, 1 = true only when I was younger than 16, 2 = true only now, 3 = true now and when I was younger than 16). Scores may range from 0 to 42 with higher scores indicating more autistic traits. Scores of 14 or above are considered indicative of autism. Internal consistency was good (Cronbach’s alpha = .79).

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). Participants completed the WEMWBS (Tennant et al., 2007), which measures positive mental wellbeing, to create the Mental Wellbeing variable. The scale contains 14 items, which reflect key indicators of positive mental wellbeing, such as experiencing positive emotions (e.g. “I’ve been feeling relaxed”), clarity of thought (“I’ve been thinking clearly”) and having surplus energy (“I’ve had energy to spare”). Items are rated on a 5-point Likert scale ranging from 1 (none of the time) to 5 (all of the time), where higher scores indicate higher levels of mental wellbeing. Scores can range from 14 to 70. In the general population scores less than 43 are indicative of low wellbeing, scores between 43 and 60 are indicative of moderate wellbeing and scores above 60 suggest high levels of wellbeing. The WEMWBS has shown good internal consistency in previous studies with autistic adults (e.g. Perry et al., 2022), as well as in the present study (Cronbach’s alpha = .90)

Generalised Anxiety Disorder Questionnaire (GAD-7). Participants completed the GAD-7 (Spitzer, Kroenke, & Williams, 2006), which measures symptoms of anxiety, to create the Anxiety variable. The scale contains 7 items, each tapping into a common symptom of GAD, asking the individual to rate how often they have experienced the symptom in the previous 2 weeks (e.g. “Feeling nervous, anxious or on edge?” and “Feeling afraid as if something awful might happen?”) on a 4-point Likert scale, from 0 (not at all) to 3 (nearly every day). Scores can range from 0 to 21, where higher scores indicate higher levels of anxiety symptoms. In the general population, scores of 10 or above are considered indicative of GAD and scores of 5, 10 and 15 can be interpreted as mild, moderate and severe levels of anxiety, respectively. The GAD-7 has previously shown good internal consistency in samples of autistic adults (e.g. Griffiths et al., 2019). The GAD-7 has good internal consistency in the present sample (Cronbach’s alpha = .87).

Patient Health Questionnaire (PHQ-9). Participants completed the PHQ-9 (Kroenke & Spitzer, 2002), which measures symptoms of depression, to create the Depression variable. The scale contains 9 items, reflecting common symptoms of depression, asking the respondent to indicate how often they have experienced the symptom in the previous 2 weeks (e.g. “Little interest of pleasure in doing things” and “Poor appetite or overeating”) on a 4-point Likert scale, from 0 (not at all) to 3 (nearly every day). Scores can range from 0 to 27, where higher scores denote higher levels of depressive symptoms. In the general population scores can be interpreted as representing mild (5 – 9), moderate (10 – 14), moderately severe (15 – 19) or severe (20 – 27) levels of depression. The PHQ-9 has previously shown good internal consistency in samples of autistic adults (e.g. Griffiths et al., 2019), which is also present in the current sample (Cronbach’s alpha = .88).

Autism Spectrum Identity Scale (ASIS). Participants completed the ASIS (McDonald, 2017), which measures how an individual identifies with being autistic, across four distinct areas; positive difference, changeability, context dependent and spectrum abilities. The scale contains 22 items about the individual’s experience of their autistic identity, which are rated on a 5-point Likert scale from 0 (strongly disagree) to 4 (strongly agree). Scores for each sub-scale can range from 0 to 4. Two subscales were used for the purpose of the present study, aggregated to compute the Positive Autistic Identity variable; Positive Difference and Spectrum Abilities. Higher scores on the Positive Difference sub-scale indicates support of the idea that being autistic is a positive difference, whereas lower scores indicate support of the idea that being autistic creates challenges (e.g. “I feel being autistic has more benefits than challenges”). Higher scores on the Spectrum Abilities sub-scale indicate a belief that there are autism-specific positive abilities, while lower scores on this sub-scale indicate a belief that their positive abilities are not related to being autistic (e.g. “Being autistic means having unique abilities”). Thus, on the Positive Autistic Identity variable, higher scores represent a more positive view of being autistic, while lower scores indicate a less positive perception of being autistic. Internal consistency for both the Positive Difference and Spectrum Abilities sub-scales were good (Cronbach’s alpha = .87, .76, respectively). Taken together, as the Positive Autistic Identity variable, the internal consistency was also good (Cronbach’s alpha = .88).

General Belongingness Scale (GBS). Participants completed the GBS (Malone, Pillow, & Osman, 2012), which measures an individual’s sense of belonging, to create the Belonging variable. The scale measures an individual’s experience of acceptance and inclusion (e.g. “When I am with other people, I feel included”), as well as experiences of exclusion and rejection (e.g. “I feel as if people do not care about me”). The scale contains 12 items that respondents must rate their agreement with on a 7-point scale from 0 (strongly disagree) to 6 (strongly agree). Scores range from 0 to 6. To our knowledge, this scale has not previously been used with a sample of autistic adults. Internal consistency in the present sample for the GBS was good (Cronbach’s alpha = .90)

Stigma Consciousness Scale (SCS). Participants completed the SCS (Link & Phelan, 2014), which measures an individual’s awareness of the stigmatised status of an aspect of their identity, to represent the Stigma variable. The original scale related to mental illness and was adapted for the purposes of the present study to focus on autism, e.g. “stereotypes about autistic people have not affected me personally”, as per a study conducted by Perry and colleagues (2022). Participants rated each item on a scale from 0 (strongly agree) to 3 (strongly disagree). Scores could range from 0 to 15, where higher scores indicate greater awareness of stigmatisation. This scale has previously shown acceptable internal consistency in a sample of autistic adults (Perry et al., 2022). Internal consistency for the SCS in the present sample was good (Cronbach’s alpha = .70)

Retrospective Bullying Questionnaire (RBQ). Participants completed an adapted version of the RBQ (Schäfer et al., 2004), which gathered information in relation to experiences of bullying at (primary and/ or secondary) school. The questionnaire asked respondents to select which types of bullying they experienced during school (if any), including physical bullying (“hitting and kicking, and having things stolen from you”), verbal bullying (“being called nasty names, and being threatened”) and/ or indirect bullying (“having lies or nasty rumours told about you behind your back, or being deliberately excluded from social groups”). It also asked participants to rate the frequency of each type of bullying they experienced on a 5-point scale from 1 (not at all) to 5 (constantly), as well as the perceived severity of each type of bullying they experienced on a 4-point scale from 1 (not at all) to 4 (extremely serious). Participants were categorised into ‘victims’ and ‘non-victims’, to create a dichotomous Bullying variable. Participants were considered ‘victims’ if they experienced one or more types of bullying, at least ‘sometimes’ (frequency) and which was at least ‘quite serious’ (perceived severity; Schäfer et al., 2004). In addition, a second bullying variable, Frequent Bullying, was computed whereby participants were considered victims if they experiences one or more types of bullying at least ‘frequently’ and which was at least ‘quite serious’.

3.2.4.4 Analysis. All analysis was conducted using SPSS Statistics package (version 26).

Preliminary analysis. Descriptive statistics for all variables were calculated and are presented in Table 8 and Table 9, separated by gender. The distribution of the scores on each variable were examined by inspecting the histograms, QQ plots and box plots for each variable. Shapiro-Wilk test statistics were also used to determine if scores were normally distributed. Due to the size of the sample, most parametric tests were considered robust enough to account for potential Type 1 errors and thus parametric tests were used. However, where there were unequal sub-sample sizes (i.e. gender), non-parametric tests were used.

Missing data. The initial dataset comprised 320 participants, who all completed the consent form. Participants who selected ‘no’ on any item in the consent from were also removed from the dataset (n = 8). Those who reported being under 18 years old were also removed from the dataset (n = 3). Participants who did not complete at least the demographic information and the first three scales (as above) were removed from the dataset (n = 73). This resulted in a final dataset comprising 236 participants.

Little’s Missing Completely at Random (MCAR) test was conducted, which indicated that missing values MCAR**,** χ^2= 2370.64, DF = 2404, p = .682. Therefore, the following methods were used to address the issue of missing data with minimal bias (Newman, 2014). When data were missing on a construct level (i.e. an entire scale was missing for a participant) or within the RBQ, multiple imputation was used to reconstruct values. SPSS was used to conduct the fully conditional specification method of multiple imputation, whereby 10 imputations were performed, and these were pooled to create the final imputed dataset. When data were missing on an item level (i.e. items were missing within a particular scale), either (1) the mean of the completed items within that scale was used to represent that participant’s scale/ construct score, or (2) the missing item was replaced with the median of the completed items in the scale (where the scale score was the sum of items and not the mean).

Estimation of Anxiety, Depression and Mental Wellbeing levels. Anxiety and Depression variables were recoded into dichotomous variables signifying whether the participant scored above or below the cut-off scores for GAD and Depression.

Similarly, the Mental Wellbeing variable was recoded into a categorical variable representing WEMWBS cut-off scores for ‘low’ ‘moderate’ and ‘high’ levels of mental wellbeing. Descriptive statistics were computed to signify the number of participants of each gender (and in the whole sample) who meet the cut-off levels for Anxiety, Depression and Mental Wellbeing.

Group comparisons. Kruskal-Wallis Tests were used to compare Income levels and Autistic Traits across genders. An Independent Samples T-test was conducted to compare levels of Autistic Traits in participants with a formal autism diagnosis, compared to those who self-identify as autistic. An Independent Samples T-test was conducted to examine differences in Positive Autistic Identity between participants diagnosed in childhood, compared to those diagnosed in adulthood.

One-way between groups ANOVAs were conducted to compare Age, Age at Diagnosis, Mental Wellbeing, Anxiety, Depression, Stigma, Belonging and Positive Autistic Identity across genders. Where the ANOVA identified a statistically significant difference, post-hoc Tukey tests were completed to conduct pairwise comparisons. The Bonferroni correction was applied to alpha values where more than one Tukey Test was conducted in order to control for Type 1 errors.

A chi-square test for independence was conducted to compare Bullying status (victim/ non-victim) across genders.

Predictors of Mental Wellbeing, Anxiety and Depression. Gender was recoded into three dummy variables representing cisgender males (reference group), cisgender females and trans people, for the purposes of correlational and regression analysis. Pearson product-moment correlations were used to examine the relationships between variables; Gender (cisgender female), Gender (trans), Age, Age at Diagnosis, Income, Autistic Traits, Mental Wellbeing, Anxiety, Depression, Stigma, Belonging, Positive Autistic Identity, Bullying (victim/ non-victim).

Three separate hierarchical regressions explored whether factors identified within Phase 1 of the present study predicted Mental Wellbeing, Anxiety and Depression outcomes. These were two ‘general factors’, which are known to be predictive of mental health difficulties in the general populations; Belonging and Bullying, and two ‘autism-specific’ factors; Autism Stigma and Positive Autistic Identity. Demographic variables were entered in the first step in order to statistically control for these variables. General factors were entered at step 2 to understand the contribution of these factors, when controlling for demographic variables. Autism-specific factors were entered at step 3, to explore their contribution to explaining the outcome variables, while controlling for demographic and general factors. These regression analyses were also conducted using the Frequent Bullying variable in place of the standard Bullying variable. However, this did not impact the results, thus the analyses as described above are presented below.

3.3 Results

3.3.1 Phase 1

Through the process of inductive thematic analysis, 6 themes comprising 16 sub-themes were developed. Theme 1, *'wide variety of mental health difficulties'*, described the wide variety of mental health experiences reported by participants, which included diagnosed mental health conditions, symptoms of mental health conditions and autism-specific features of mental health, including meltdown and autistic burnout. Theme 2, *'individual context and significant events'*, illustrated a range of individual and contextual factors that participants felt impacted their mental health. This included genetic and physical factors, their individual profile of functioning skills and significant or traumatic events they experienced in their lives. Theme 3, *'social connection and support'*, outlined the importance of social connection and social support. Participants described people in their lives who promoted their mental health, through providing a sense of belonging, acceptance and support. Theme 4, *'autistic identity and self-perception'*, described individual experiences of coming to the realisation that they are autistic (which may or may not include a formal diagnosis), developing an understanding of what it means for them to be autistic and the process of embracing their own autistic identity. Theme 5, *'stigmatisation and victimisation'*, reported on participants' descriptions of others' negative attitudes and harmful behaviours towards them and the impact of these on their mental health. The way they were treated was generally put down to them being autistic, which had an effect on how they viewed themselves and their autistic identity. Finally, theme 6, *'navigating the neurotypical world'*, described challenges that arose while interacting with the neurotypical world that was often incompatible with their needs or preferences. As a result, participants often described a build-up of small day-to-day stressors that become too overwhelming to manage. See Appendix P for a full description of each theme and sub-theme and Table 7 for an overview of themes, sub-themes and illustrative quotes.

Table 7

Overview of thematic analysis results Phase 1

Theme	**Sub-theme**	**Illustrative quote**
1. Wide variety of mental health difficulties	Types of mental heath difficulties	*"So a lot… at 16 I developed severe anxiety and social anxiety and then, when I was 21 I was diagnosed with depression as well one kind of wanted a bleeding into the other and I've been dealing with both since."* (Ptp. 12, age 23, cisgender male)
	Autism-centric mental health features	*"I can't do this and I completely just shut, what I recognize now was I shut down. I stopped talking, I stopped being able to do anything for a couple of days and I'm not sure if it was a burnout or a shutdown but it felt like it lasted a couple of days, where she just had to take me out of school."* (Ptp. 16, age 31, cisgender female)
	Active self-management of mental health difficulties	*"I tried to read a lot and I play alot of video games and stuff like that. I try to find interests a lot because they're good distractions if I need them."* (Ptp. 8, age 19, agender)
2. Individual context &	Biological or physical factors	*"…physical health has a major effect on mental health, and I know that a large*

significant events		*part of it is the fact that pain is exhausting. And that's always going to have an effect on mental health um but yeah when I'm having a high anxiety time, it definitely contributes to the pain. When I'm having pain, it contributes to depression."* (Ptp. 9, age 35, non-binary)
	Functioning difficulties	*"But in things that I would be high functioning and I'm low functioning [in] others and that's something that people don't seem to realize with autism like I'm described as quite conscientious and well spoken and articulate, but I will forget to eat."* (Ptp. 5, age 19, non-binary)
	Contextual factors & significant life events	*"I mean, I was the one who was trying to save her. I feel like I've spent my entire life trying to save my family, you know it's like it's always been my job, for some reason I was always seen as a strong one. Yeah I still am, I still get that, even now I still get that. You know people think that I'm really tough and hard and thick skinned and I'm not at all, I never have [been] even a little bit."* (Ptp. 17, age 50, non-binary)
3. Social connection and	Belonging, acceptance &	*"Those who've always toughed it out and sort of supported me, had the*

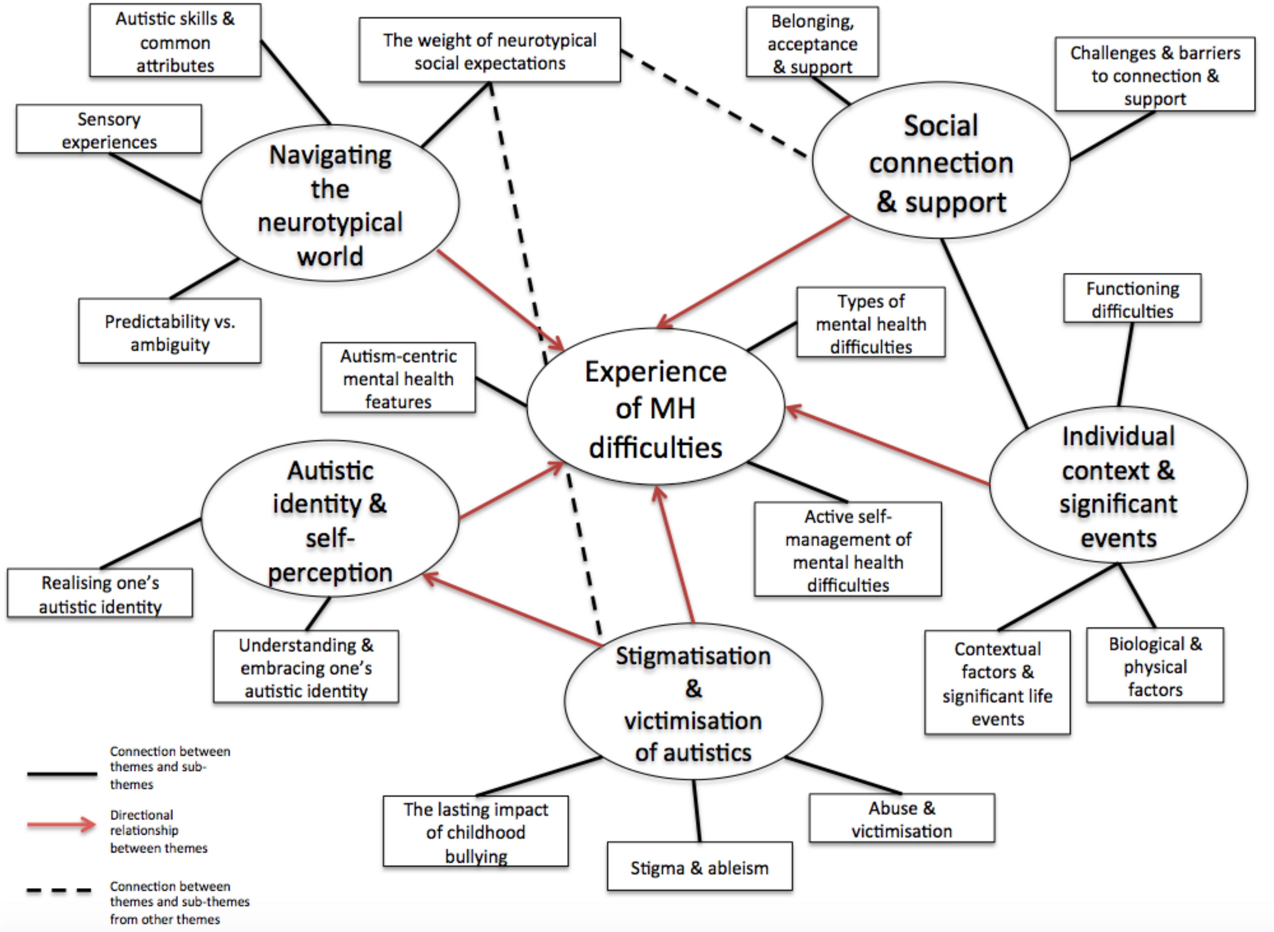
support	support	*conversations about kind of my own experiences with autism, so they've made the effort to learn as well, which is, which has been really kind of helpful helping me kind of protect my mental health more than sort of the ones who not really or any fault of their own as well somewhat damaged it."* (Ptp. 12, age 23, cisgender male)
	Challenges and barriers to connection and support	*"It is hard to make and keep friends as the minute they see I am not like them they walk away"* (Ptp. 20, age missing, cisgender female)
4. Autistic identity and self-perception	Realising one's autistic identity	*"Her understanding of autism was just a wise skinny teenage boy that couldn't make eye contact and always did a flapping hands [...] stimming."* (Ptp. 5, age 19, non-binary)
	Understanding and embracing one's autistic identity	*"It was just a massive relief to me because, when you do have mental health issues, there is a kind of shame, Especially in this culture as well, like so I felt kind of ashamed about it, and I felt that, like I had done it I let it get this bad, but when I got diagnosed it was kind of like well you didn't have all the information, And because he didn't have all the information you couldn't fix what you needed*

		to fix or change what you needed to change or adapt.” (Ptp. 2, age 36, cisgender male)
5. Stigmatisation and victimisation	The lasting impact of childhood bullying	*“I was a weird kid and it's one of those things of like people say that they don't make fun of autism but oh boy do they make fun of autistic behavior.”* (Ptp. 9, age 25, non-binary)
	Abuse and victimisation	*“Now, obviously, due to my past traumas, the molestation, rape and then the attack from my father, it all kind of made me very, very weary of men, I’m still very weary of men at this stage so when I shared a house with another man, I was terrified, so that definitely added to negative impacts.”* (Ptp. 16, age 31, cisgender female)
	Stigma and ableism	*“I went on a date with a girl a few years ago and this was around the time I was figuring out I was autistic and I mentioned it to her and she said ‘you can control it, right?’ as if, you know, something is wrong with me. That was just one example of explicit ableism.”* (Ptp. 3, age 26, cisgender male)
6. Navigating the	Sensory experiences	*“By in fifth and sixth year I started having a lot more sensory overload in class*

neurotypical world		*and I started to get really scared and nervous that I was gonna have a meltdown there in front of everybody."* (Ptp. 5, age 19, non-binary)
	Predictability vs. ambiguity	*"I'm very happy at work. I've been there for 20 years now, so I know the people and they know me. But anything different that's out of the routine, well, that brings back a spike in stress levels."* (Ptp. 4, age 42, cisgender female)
	Autistic skills and common attributes	*"At the end of the day, it's an important thing to have in mind that sometimes we're sensitive to the world in a different way and that's not a bad thing or a good thing, but it's something that people need to understand, in order to truly have like equitable the world in terms of like how we distribute our mental health services and everything."* (Ptp. 14, age 24, cisgender female)
	The weight of neurotypical social expectations	*"I like I put down to mimicking others like, literally because it seemed like the thing to do, because, like I just didn't want to be bullied so what I did was I learned I watched the people who weren't getting bullied and tried to mimic them and their personalities."* (Ptp. 2, age 36, cisgender male)

Figure 3

Thematic analysis of factors that impact the mental health of autistic adults



3.3.2 Phase 2

3.3.2.1 Demographic characteristics

Kruskal-Wallis Tests indicated no statistically significant difference between genders in terms of Income or Autistic Traits. A one-way between groups ANOVA revealed no statistically significant difference in Age or Age at Diagnosis (formal diagnosis or self-identification) across genders. An independent samples t-test revealed no statistically significant difference between levels of Autistic Traits in formally diagnosed compared to self-identified participants.

3.3.2.2 Levels of wellbeing and mental health

See Table 8 for Mental Wellbeing, Anxiety and Depression scores by gender.

Mental Wellbeing. A one-way between groups ANOVA revealed no statistically significant difference in mental wellbeing across genders. According to WEMWBS cut-offs scores, 0.8% of participants reported high levels of mental wellbeing (n = 2), while 30.1% reported moderate levels (n = 71) and 69.1% reported low levels of mental wellbeing (n = 163).

Table 8

Overview of Phase 2 study variables by gender

Variable	Min - max	Cis male (n = 47) Mean (SD)	Cis female (n = 171) Mean (SD)	Trans (n = 17) Mean (SD)	Total (n = 236) Mean (SD)
Wellbeing (n = 236)	14 - 70	41.42 (8.78)	38.13 (8.61)	37.18 (9.28)	38.77 (8.77)
Anxiety (n = 236)	0 - 21	9.60 (4.94)	12.86 (5.44)	13.06 (5.71)	12.19 (5.50)
Depression (n = 236)	0 - 27	11.69 (6.71)	13.08 (6.72)	16.47 (6.84)	13.03 (6.78)
Age at diagnosis (n = 225)	3 - 65	26.82 (16.92)	30.36 (11.85)	24.03 (11.59)	29.06 (13.06)
Autistic traits (n = 222)	0 - 42	30.63 (7.68)	31.63 (8.30)	32.94 (7.84)	31.55 (8.11)
Stigma (n = 218)	0 - 15	9.71 (2.75)	10.34 (2.54)	11.47 (2.15)	10 (2.58)
Belonging (n = 216)	0 - 6	2.94 (1.21)	2.86 (1.07)	2.35 (1.14)	2.84 (1.11)
Positive Autistic Identity (n = 221)	0 - 4	1.99 (.60)	2.34 (.70)	2.38 (.91)	2.28 (.71)

Anxiety. 63.6% of participants in the present sample screened above the cut-off for GAD. A one-way between groups ANOVA revealed a statistically significant difference in Anxiety across genders, F(2, 232) = 7.05, *p* = .001. A post-hoc Tukey Test indicated that cisgender women had higher levels of Anxiety than cisgender men (*p* = .002, 95% CI = -5.35, -1.18). Another post-hoc Tukey Tests showed no statistically significant difference in anxiety levels between cisgender men and trans people, once the Bonferroni correction was applied (*p* = .060; 95% CI = -7.04, .12). Cisgender women and trans people were not compared, due to similar means.

According to GAD-7 cut-off scores, 64.7% of trans people, 68.4% of cisgender women and 46.8% of cisgender men screened positive for GAD. In addition, 41.2% of trans people, 42.7% of cisgender women and 12.8% of cisgender men reported anxiety symptoms in the severe range.

Depression. 65.7% of participants in the present sample (n = 155) screened above the PHQ-9 cut-off score for depression. A one-way between groups ANOVA revealed a statistically significant difference in depression symptoms across genders, F(2, 232) = 3.16, *p* = .022. A Post-hoc Tukey Test indicated that trans participants reported higher levels of depression symptoms than cisgender men, (p = .034, 95% CI = -9.27, -.29). A Tukey Test comparing cisgender women and cisgender men was not statistically significant.

According to PHQ-9 cut-off scores, 76.5% of trans people, 67.8% of cisgender women and 55.3% of cisgender men screened positive for depression. In addition, 41.2% of trans participants reported severe levels of depression, while 19.9% and 12.8% of cisgender females and males, respectively, reported depression levels in the severe range. Furthermore, 64.7% of trans participants, 48.5% of cisgender women and 53.2% of cisgender men reported experiencing suicidal ideation on at least half of the days in the previous two weeks.

3.3.2.3 Levels of independent variables

See Table 8 for scores on independent variables, displayed by gender.

Positive Autistic Identity. A one-way between groups ANOVA revealed a statistically significant difference in Positive Autistic Identity across genders, F(2, 217) = 4.46, p = .013. Post-hoc Tukey Tests indicated that cisgender females had higher levels of Positive Autistic Identity than cisgender males (p = .022, CI 95% = .067, .633) and showed no statistically significant difference between trans people and cisgender males. Cisgender women and trans people were not compared, due to observed similar means.

An independent samples t-tests showed that there was a statistically significant difference in Positive Autistic Identity between those diagnosed in childhood compared to those diagnosed in childhood, t (227) = -3.25, p < .001, d = 0.54. Those diagnosed in adulthood reported higher levels of Positive Autistic Identity (m = 2.36) than those diagnosed in childhood (m = 1.98).

Belonging. A one-way between groups ANOVA revealed no statistically significant difference in Sense of Belonging across genders.

Stigma. A one-way between groups ANOVA revealed a statistically significant difference in Stigma reported across genders, F(2, 214) = 2.94, p = .028. A post-hoc Tukey Tests indicated that trans people reported higher levels of Stigma, compared to cisgender males (p = .023, CI 95% = -3.49, -.03). No other post-hoc tests were completed due to observed similar means.

Bullying. A chi-square test for independence indicated no significant association between Gender and Bullying, χ^2 (2, n = 212) = 3.47, p = .176. According to the RBQ, 64.8% of respondents reported being a victim of bullying in childhood or adolescence. 23.9% were victims of physical bullying, 50.9% were victims of verbal bullying and 58.2% were victims of indirect bullying. See Table 9.

Table 9
Childhood bullying experiences by gender

	Cisgender male n (%)	Cisgender female n (%)	Trans n (%)	Total n (%)
Victim (n = 212)	27 (64.3)	97 (62.6)	13(86.7)	138 (64.8)
Physical bully victim (n = 209)	16 (39)	30 (19.6)	4 (28.6)	50 (23.9)
Verbal bully victim (n = 212)	23 (54.8)	75 (48.4)	9 (64.3)	108 (50.9)
Indirect bully victim (n = 212)	19 (46.3)	91 (59.1)	13 (76.5)	124 (58.2)

Table 10

Correlations between all variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. Age												
2. Cis. Female	.062											
3. Trans	-.159*											
4. Age at diag	.872***	.147*	-.112									
5. Income	.164*	.042	.044	.244***								
6. Wellbeing	.184**	-.110	-.049	.081	.151*							
7. Anxiety	-.201**	.190**	.043	-.134*	-.100	-.605***						
8. Depression	-.202**	.008	.141*	-.138*	-.153*	-.715***	.724***					
9. Aut. traits	.100	.019	.050	.109	-.068	-.103	.010	.052				
10. Stigma	-.033	.023	.132	.006	.063	-.218**	.244***	.231**	.006			
11. Belonging	-.057	.034	-.127	-.129	.080	.523***	-.363***	-.441***	-.134	.207***		

12. Pos. Aut. Identity	.073	.150*	.043	.178**	.106	.254***	-.137*	-.235***	.163*	.127	.284***	
13. Bullying	-.159*	-.070	.127	-.147*	-.082	-.115	.173*	.234**	-.145*	.156*	-.219***	-.115

*p < .05, ** p < .01, ***p < .001.

3.3.2.4 Predictors of Mental Wellbeing

Table 10 shows the results of all correlations between variables in the present sample. Age, Income, Autism Stigma, Belonging and Positive Autistic Identity were all significantly correlated with Wellbeing. However, Gender, Age at Diagnosis, Autistic Traits and Bullying were not correlated with Mental Wellbeing and these variables were therefore not included in the regression model.

A hierarchical regression was performed with Mental Wellbeing as the outcome variable (see Table 11). To statistically control for these variables, Age and Income were entered into the first step, explaining 4.9% of the variance in Mental Wellbeing, F(2, 187) = 4.792, $p = .009$. Belonging was added in the second step, which accounted for a further 27.6% of Mental Wellbeing scores, F(1, 186) = 75.885, $p < .001$. Finally, in the third step autism-specific variables were added; Autism Stigma and Positive Autistic Identity. These variables accounted for a further 2.4% of the variability in Mental Wellbeing, F(2, 184) = 3.386, $p = .036$. The total variance explained by the final model is 34.8%, F(5, 184) = 19.674, $p < .001$. In the final model, the following (listed in order of predictive ability) were statistically significant predictors of Mental Wellbeing: Belonging ($\beta = .465$, p <.001), Age ($\beta = .184$, $p = .001$) and Autism Stigma ($\beta = -.136$, $p = .031$).

Table 11

Hierarchical regression for Mental Wellbeing

	B	SE B	β
Step 1			
Constant	2.163	.064	
Age	.129	.057	.163*
Income	.659	.384	.124
Step 2			
Constant	20.352	2.296	
Belonging	4.175	.479	.528***
Bullying	.817	.781	.071
Step 3			
Constant	23.633	3.410	
Autism Stigma	-.462	.212	-.136*
Positive Autistic Identity	1.436	.784	.117

Note: $R^2 = .049$ for step 1, $\Delta R^2 = .276$ for step 2, $\Delta R^2 = .024$ for step 3 ($p < .001$).

*$p < 0.05$, **$p < 0.01$ ***$p < 0.001$

3.3.2.5 Predictors of Anxiety

Age, Gender (cisgender female), Age at Diagnosis, Bullying, Belonging, Autism Stigma and Positive Autistic Identity were all significantly correlated with Anxiety. However, Gender (trans), Income and Autistic Traits were not correlated with Anxiety and thus were not included in the regression model.

A hierarchical regression was performed with Anxiety as the outcome variable (see Table 12). To statistically control for these variables, Age, Age at diagnosis and Gender (cisgender female) were entered into the first step, explaining 8.4% of the variance in Anxiety, F(3, 183) = 5.578, $p = .001$. Next, Belonging and Bullying were added to the model, which accounted for significantly more of the variance (15%) in Anxiety scores, F(2, 181) = 17.680, $p < .001$. Finally, autism-specific variables, Autism Stigma and Positive Autistic Identity, were added to the model in step three, which significantly explained a further 2.7% of the variance in Anxiety levels, F(2, 179) = 3.330, $p = .038$. The final model accounts for 26.1% of the variance in Anxiety, F(7, 179) = 9.032, p < .001. Within this final model, the following (listed in order of predictive ability) were predictive of Anxiety: Belonging ($\beta = -.314$, $p < .001$), Gender (cisgender female; $\beta = .226$, $p = .001$), and Autism Stigma ($\beta = .169$, $p = .013$).

Table 12

Hierarchical regression for Anxiety

	B	SE B	β
Step 1			
Constant	14.247	1.443	
Age	-.148	.072	-.299*
Age at diagnosis	.041	.062	.099
Gender: female	2.393	.891	.194**
Step 2			
Constant	18.539	1.856	
Belonging	-1.840	.338	-.371***
Bullying	.817	.781	.071
Step 3			
Constant	15.497	2.491	
Stigma	.361	.144	.169*
Positive Autistic Identity	-.633	.558	-.082

Note: $R^2 = .084$ for step 1, $\Delta R^2 = .15$ for step 2, $\Delta R^2 = .027$ for step 3 ($p < .001$).

*$p < 0.05$, **$p < 0.01$ ***$p < 0.001$

3.3.2.6 Predictors of Depression

Age, Gender (trans), Age at Diagnosis, Income, Bullying, Belonging, Autism Stigma and Positive Autistic Identity were all significantly correlated with

Depression. However, Gender (cisgender female) and Autistic Traits were not correlated with Depression and thus were not included in the regression model.

A hierarchical regression was performed with Depression as the outcome variable (see Table 13). To statistically control for these variables, Age, Gender (trans), Age at Diagnosis and Income were entered into the first step, which explained 8% of the variance in Depression scores, F(4, 182) = 3.975, *p* = .004. Next, Belonging and Bullying were added to the model, which significantly predicted a further 18.6% of the variance in Depression scores, F(2, 180) = 22.759, *p* < .001. Finally, autism-related variables, Autism Stigma and Positive Autistic Identity, were added to the model, which accounted for another significant portion of the variance (3.2%), F(2, 178) = 4.118, *p* = .018. The final model accounted for 29.8% of the variance in Depression scores (F(8, 178) = 9.465, p < .001). Within this final model, the following (listed in order of predictive ability) were predictive of Depression: Belonging (β = -.334, p < .001), Age (β = -.289; p = .032), Autism Stigma (β = .158, p = .019) and Positive Autistic Identity (β = -.145, p = .041).

Table 13

Hierarchical regression for Depression

	B	SE B	β
Step 1			
Constant	18.579	1.798	
Age	-.210	.090	-.345*
Age at diagnosis	.110	.077	.213
Gender: trans	3.057	1.886	.117
Income	-.630	.303	-.154*
Step 2			
Constant	11.316	2.626	
Belonging	-2.513	.414	-.411**
Bullying	1.434	.946	.101
Step 3			
Constant	22.007	2.975	
Autism Stigma	.415	.175	.158*
Positive Autistic Identity	-1.381	.672	-.145*

Note: $R^2 = .080$ for step 1, $\Delta R^2 = .186$ for step 2, $\Delta R^2 = .032$ for step 3 ($p < .001$).

*$p < 0.05$, **$p < 0.01$ ***$p < 0.001$

3.4 Discussion

Autistic adults report higher levels of mental health difficulties compared to the population as a whole (e.g. Hollocks et al., 2021; Lai et al., 2019), but the reasons for this are not yet clear within the scientific literature. The first aim of the present study was to understand the factors that impact the mental health and wellbeing of autistic adults, from the perspective of autistic adults themselves. Interviews with autistic adults allowed us to develop an overview of the complex and interconnected array of factors that they believe impacted their mental health throughout life. These included factors that are known to impact the mental health of the population as a whole, such as traumatic life events, social connectedness, and victimisation (including bullying during childhood), as well as factors that are more specific to the autistic experience, such as autism-related stigma, receiving a diagnosis of autism and developing an identity as an autistic person. The second (quantitative) phase of the present study examined factors that were identified in the qualitative phase and revealed that feelings of belonging and autism-related stigma were significant predictors of mental wellbeing, anxiety and depression. In addition, younger age was associated with higher levels of depression and lower levels of wellbeing, while being a cisgender female predicted higher levels of anxiety. Integrated findings are described below under headings related to topics that were identified.

3.4.1 Experiences and levels of mental health difficulties and wellbeing

The first aim of the present study was to assess the mental health of a sample of autistic adults in Ireland, as well as to understand any gender differences in their mental health and wellbeing. Overall, our findings indicate that this sample of autistic adults in Ireland, who were recruited via social media advertising by autism charity AsIAm, experienced high levels of common mental health conditions (anxiety and depression), as well as experiencing a wide range of other diagnosed mental health conditions, symptoms indicative of mental health conditions and autism-specific features of mental health difficulties.

In line with qualitative findings, the quantitative findings indicated that this sample of autistic adults living in Ireland reported high levels of anxiety and depression. That is, over 60% of autistic adults in the present study screened above the cut-off score for GAD, whereas another study conducted within a similar timeframe indicated that 20% of the general population in Ireland score above this cut-off (Hyland et al., 2021). Moreover, cisgender females reported significantly higher levels of anxiety than cisgender men and over 40% of cisgender females and trans people reported anxiety symptoms in the severe range. Similarly, over 65% of autistic adults in the present study screened above the cut-off score for depression, while 22.8% of the general population of Ireland are estimated to score above this cut-off (Hyland et al., 2021). Trans individuals were at the highest risk for depression, whereby 75% screened above the cut-off. Furthermore, 65% of trans people and approximately 50% of cisgender people reported experiencing suicidal ideation on at least half of the days in the previous two weeks. In terms of mental wellbeing, less than 1% of participants in the present study reported high levels of wellbeing, while 70% had wellbeing levels in the ‘low’ range. The qualitative data showed that in addition to anxiety and depression, participants also reported symptoms and/ or diagnoses of a wide range of other mental health conditions, such as OCD, EUPD and Bipolar Disorder, as well as autism-specific features of mental health, for example alexithymia and meltdowns.

These high levels of anxiety and depression symptoms, as well as the range of mental health conditions reported in this sample, are in keeping with previous studies conducted across the world (Lai et al., 2019; Hollocks et al., 2019; Griffiths et al., 2019; Hull et al., 2021). Similarly, the levels of mental wellbeing reported in the present study are similar to those reported in a study based in the UK (Perry et al., 2022). With regard to gender, our findings show that cisgender women had higher levels of anxiety than cisgender men, which was contrary to our expectation, based on previous findings in relation to prevalence of anxiety disorders (Hollocks et al., 2019; Lai et al., 2019). This difference could be due to the method of measuring anxiety; while the present study quantified symptoms of GAD, other studies examine rates of formal diagnoses of GAD (Hollocks et al., 2019; Lai et al., 2019). Looking to studies that have measured anxiety symptoms, findings are mixed, with some reporting no gender differences (Cage et al., 2018; Hull et al., 2021), but notably one large study by Sedgewick and colleagues (2021) also reported that females experienced increased levels of anxiety. It should also be noted that the rate of diagnosed anxiety disorders in the present sample is high, especially for females (54% among cisgender females, 40% in cisgender males). This may point to a biased sample, or particularly high rates of anxiety among autistic women in Ireland, which could both account for the gender differences in reported anxiety symptoms.

3.4.2 Predictors of mental health and wellbeing

3.4.2.1 Individual context and significant events. Individual and contextual factors were reported to impact the mental health of autistic adults in the present study. This included genetic factors, family-related factors, socio-economic factors and wider contextual issues (e.g. COVID-19). This finding is predominantly based on the qualitative data, as the quantitative analysis did not examine this topic. Interviewees described suspected genetic predispositions to developing mental health difficulties, or contextual factors, such as mental ill health of a parent or living in poverty, which impacted their own mental health. The quantitative data did compliment these findings, providing an overview of participants demographic characteristics, thus giving insight into the life contexts of the participants, which may be indicative of the functioning (e.g. high level of unemployment) and contextual issues (e.g. proportion of people living on low incomes) raised in the qualitative phase of the study. However, these were not explored quantitatively in relation to mental health or wellbeing, with the exception of income level, which was shown to have no link. The qualitative findings are in keeping with previous literature, which has shown that parental stress and mental ill health impacts the mental health of their children, whether they are autistic or not (McAdams et al., 2015; Yorke et al., 2018) and that COVID-19 had a significant effect on wellbeing and depressive symptoms (Hedley et al., 2021).

3.4.2.2 Victimisation and bullying. According to participant perspectives, experiences of victimisation including sexual abuse or assault, interpersonal victimisation and bullying during childhood and/ or adolescence impacted their mental health and wellbeing. However, the quantitative findings showed no relationship between childhood bullying and mental health or wellbeing in adulthood. That is, the link between bullying and wellbeing and mental health identified in the qualitative results was not borne out by the quantitative data. The quantitative data did not explore any other forms of victimisation. One possible conclusion is that bullying may impact autistic young people's mental health in the short to medium-term, but the long-term the impact is insignificant. Indeed, previous research has indicated that the negative impacts of bullying on autistic young people is evident after 12 months (Rodriguez, Hartley, & Drastal, 2021). Alternatively, perhaps the impact of bullying was accounted for by other factors in the model, such as a lower sense of belonging, which was triggered by the history of bullying. Otherwise, there may have been a problem with how participants were categorised into one of two groups; those who were bullied and those who were not. Examining the bullying on a continuum of frequency or severity may be necessary to understand the long-term impact of childhood bullying. The quantitative results indicated that 65% of the adult participants had experienced physical, verbal and/ or indirect bullying during their school years. This is similar to Maïano and colleagues (2015) who concluded that autistic people are at higher risk of bullying during childhood and adolescence.

As mentioned previously, the qualitative data outlined a range of victimisation and abuse experiences, which the participants believe impacted their mental health throughout life. Although the quantitative data in the present study did not examine the impact of victimisation (aside from data on childhood bullying), previous research has investigated victimisation of autistic adults, indicating that autistic people are more likely to experience adverse life events and are perhaps especially at risk for sexual or interpersonal crimes (Forster & Pearson, 2020; Weiss & Fardella, 2018; Pecora et al., 2019; Rumball et al., 2021). Indeed, such research also demonstrated that these life events are related to the development of mental health difficulties of autistic people (Hollocks et al., 2020). Thus, while these events are predictive of mental health difficulties in the population as a whole (Hillberg et al., 2011; Lagdon et al., 2014; Takizawa et al., 2014), a higher incidence of such events may partially account for the increased level of mental health difficulties in autistic people.

3.4.2.3 Social belonging and othering. The experience of social belonging emerged as a key factor in predicting the mental health outcomes of autistic adults within both qualitative and quantitative findings. That is, within the qualitative accounts individuals described the positive impact of friendships and relationships where they are accepted and their needs and preferences are accommodated. On the other hand, experiences of social exclusion and isolation, along with associated loneliness, were named as causes of poor mental health by participants. The quantitative results showed that feeling accepted and included within one's social circle reduced levels of depression and anxiety, while increasing levels of positive mental wellbeing. Similarly, experiences of being excluded and isolated were related to poorer mental health and wellbeing. Similar reports of social exclusion and accompanying loneliness and distress have been highlighted in previous qualitative studies (e.g. Bernardin et al., 2021; Leedham et al., 2020) and indeed quantitative evidence is emerging showing direct links between belonging, perceived acceptance by others and loneliness, and mental health and wellbeing (Cage et al., 2018; Moseley et al., 2021; Pelton et al., 2020; Ressel et al., 2020).

The qualitative findings also identified barriers and challenges that autistic adults face in developing meaningful social connections that can provide this sense of belonging. Participants described more challenges and misunderstandings with neurotypical (or non-autistic) peers compared to autistic peers, which could even lead to complete deterioration of the friendships. A sense of belonging with neurotypical people required more effort, both on the part of the autistic person and the neurotypical person, so often this depended on the neurotypical person's willingness to understanding and adapt to their autistic friend. Likewise, experiences of exclusion and isolation were often linked to their differences not being accepted, as participants report feeling like a 'misfit' and being made aware that differences were negative from a very early age. As such, belonging with other autistic people seemed to occur more naturally, where there was a natural 'fit' and an immediate sense of understanding and support. This incongruence between autistic and non-autistic people may be understood through the theory of Double Empathy (Milton, 2017), which posits that it is not a deficit in social ability on the part of the autistic individual, but rather a mutual incompatibility between autistic and non-autistic people that gives rise to the difficulties that autistic people experience (in addition to the assumption that the neurotypical approach is superior). In support of this, recent research exploring autistic adults' relationships with autistic and non-autistic friends and family, which highlights increased ease, understanding and belonging when interacting with autistic people compared to neurotypical people (Crompton et al., 2020).

3.4.2.4 Stigma. Autism-related stigma was identified as an important factor in predicting mental health and wellbeing of autistic adults in both the qualitative and quantitative phases of the study. Interviewees described how autism-related stigma impacted their mental health throughout life, including reports of both explicit and implicit stigma against them. Participants also described how they coped with this stigma through self-advocacy, educating others about autism and masking to protect themselves. The quantitative data showed that autism-related stigma was predictive of mental wellbeing, anxiety and depression, but did not examine methods of coping with stigma. Stigma can be conceptualised as the result of a characteristic, behaviour or social category that is discrediting to an individual. That is, stigma results from a disjuncture between one's social identity and the idealised social norm in one's current environment (Goffman, 1968). For the case of autistic people, stigma occurs due to their divergence from the neurotypical social norm, thus, not only are they considered 'different' (as described previously), but this difference is also perceived negatively. The present study offers support to the growing body of evidence indicating that autistic people experience poor mental health and wellbeing, partially as a consequence of stigma (Botha & Frost, 2020; Perry et al., 2022). Stigma is also linked with a range of other negative outcomes, which are in and of themselves risk factors for mental health, such as social exclusion and victimisation (Goffman, 1968), suggesting that stigma may be an underlying factor explaining in these experiences for autistic people.

Qualitative findings report that in response to stigma, participants felt that their natural approaches to communication and socialising were inferior to those of neurotypical people, forcing them to instead conform to neurotypical social expectations through masking. They described masking in order to be accepted and not victimised or shunned by their neurotypical peers. However, even if masking provided some protection, it also yielded harmful consequences for wellbeing and mental health, such as anxiety, exhaustion and even burnout. Such pressures to mask and the associated exhaustion and distress are also well documented in previous literature (e.g. Cook et al., 2021) and are inextricably linked to the experiences of stigma that autistic people face (Pearson & Rose, 2021). That is, when an individual is stigmatised in some way, they engage in ‘impression management’ (in the case of autistic people, by masking their autistic traits), in order to conceal their stigmatised status or avoid additional stigmatisation. Thus, masking must be considered within the context of stigma and managing risk of discrimination and victimisation.

3.4.2.5 Autistic identity and self-perception. Overall, the process of receiving a diagnosis and developing one’s sense of identity around this was identified as an important factor in the mental health and wellbeing of autistic adults. However, the qualitative and quantitative findings were only in partial agreement in terms of the nuances of the association. Participants who were diagnosed in adulthood described a journey of self-discovery and self-acceptance following diagnosis, which promoted their wellbeing and mental health. In keeping with this, quantitative findings showed that those diagnosed in adulthood had higher levels of positive autistic identity and this was in turn associated with lower levels of depression (though it was not related to anxiety or wellbeing). Interviewees also expressed regret and frustration that they did not receive a diagnosis earlier in life, which they believed would have helped them to avoid a lot of suffering. However, quantitative data did not support a link between younger age of diagnosis and increased wellbeing, which is contrary to previous research on the topic (Oredipe et al., 2022). There are several possible explanations for this discrepancy. For instance, perhaps receiving a diagnosis in childhood is related to having higher support needs, which may or may not be met by the available services. Indeed, previous research has shown that unmet support needs are predictive of mental health difficulties (Cassidy et al., 2018). Alternatively, perhaps the stigma associated with being autistic is starker as a child; participants in the present study who were diagnosed in childhood described how the negative perception of others (e.g. parents) impacted on their own self-perception as an autistic person. Taken together, we might initially conclude that receiving a diagnosis in adulthood is better for mental health than receiving a diagnosis in childhood. However, it must be borne in mind that those diagnosed in adulthood describe struggling throughout their younger years without a diagnosis. Thus, perhaps a more accurate conclusion is that when a child (or adult) is diagnosed with autism, a positive autistic identity must be fostered, in order to protect their mental health throughout life. In keeping with this conclusion, previous qualitative studies have demonstrated similar reported benefits of diagnosis (e.g. Leedham et al., 2020; Seers et al., 2021), as well as a quantitative relationship between acceptance and contentment with one's autistic identity, and wellbeing and depression (Cage et al., 2018; Maitland et al., 2021; Perry et al., 2022).

While there are clear perceived benefits of receiving a diagnosis, assessment and diagnosis were not always easily accessible to participants, according to the qualitative findings. Interviewees reported barriers related to professionals understanding of autism, in particular stereotyped understandings of autism which are biased against those who are not white males. Though the quantitative data did not show a gender difference in age of diagnosis, therefore not supporting a gender bias in diagnosis. There were also general service-related barriers, particularly in adulthood due to a lack of an adult autism assessment service in the Irish public health system.

3.4.2.6 Navigating the neurotypical world. The qualitative results discussed a range of autistic needs and preferences that were not catered to in the neurotypical world (quantitative data regarding this topic were not collected). For instance, interviewees described stressful experiences in relation to the sensory environment and situations that lack predictability or clarity. They described how particular sensory stimuli can cause distress and panic and as a result impact on their ability to engage in desired activities, including work and social activities. In terms of the need for predictability, participants reported that routine and sameness supports their mental health, while unexpected situations or changes can trigger stress. Previous research has also shown both qualitatively and quantitatively that sensory experiences and uncertainty impact on mental health, in particular anxiety (Robledo et al., 2012; Hwang et al., 2019). These daily challenges and the resulting impact on mental health and wellbeing maybe understood within Spoon theory (Miserandino, 2003). Spoon theory was first proposed by Christine Miserandino (2003) in relation to chronic illness and it suggests that an (autistic) individual has a limited number of “spoons” each day (which varies greatly between individuals and from day to day) and every activity they engage in will “use” a spoon (or multiple spoons). For autistic people, situations with particular sensory stimuli or with high degrees of uncertainty may “use more spoons” than they would for a neurotypical person. Thus, they must consciously decide which activities to engage in each day (from brushing their teeth, to going to a party), so as not to deplete their level of “spoons”, which could cause exhaustion or burnout.

3.4.3 Clinical and research implications

The high levels of anxiety and depression and low levels of wellbeing reported by the autistic adults in the present study underline the importance of identifying possible avenues for the prevention and treatment of mental health conditions in this group. A phenomenon that appears to underpin several of the contributing issues for autistic adults is autism-related stigma. Thus, one method of preventing the development of mental health difficulties may be tackling autism-related stigma in society and within communities, perhaps via anti-stigma and autism-acceptance campaigns (for examples, see Birnschein et al. (2021) and Jones et al. (2021)). It may also be beneficial for both autistic and non-autistic people to learn about the communication styles and social preferences of the other group, allowing for greater understanding between groups and perhaps increased feelings of inclusion and belonging for autistic individuals. In addition, connecting with the autistic community appears to offer unique benefits in terms of fostering a sense of belonging and inclusion (Crompton et al., 2020). Future research may seek to gain a deeper understanding of how a sense of belonging can be fostered both within and outside of the autistic community.

Although childhood bullying was not quantitatively linked to current mental health or wellbeing in the present study, the convincing reports by interviewees suggest that future research should investigate if and how childhood bullying impacts on the long-term mental health of autistic people. Utilising the experience and expertise of autistic people, as well as longitudinal research design may be helpful in exploring this research question.

Considering the demonstrated benefits of realising one’s autistic identity and the associated journey of self-understanding and self-acceptance, barriers to accessing assessment and diagnosis should be removed. This may be achieved through increased autism awareness and understanding for the public, clinician training and the development of adult autism assessment services. Moreover, the present study points to the benefits of a positive autistic identity, suggesting that deficit-focussed narratives may be unhelpful or even damaging. Future research could explore whether neurodiversity aligned assessments (Brown et al., 2021) or strength-informed assessments (Courchesne et al., 2015) could promote a more positive autistic identity among those receiving assessments. Furthermore, post-diagnostic peer-led support may provide further support in developing a positive autistic identity, as well as creating connections with other autistic people (Crompton et al., 2022).

With regard to the impact of everyday stressors associated with an incompatible neurotypical world, the concept of universal design may provide a useful framework. Universal design suggests eliminating environmental barriers to make conditions more accessible (Steinfeld & Maisel, 2012), which in the case of autistic people with sensory sensitivities or a difficulty with unpredictability, may include providing clear visual supports or reducing sensory stimuli in public spaces (Milton et al., 2016). Individuals may also benefit from applying spoon theory as an approach to managing their internal resources, which has shown benefits in a sample of autistic young people with regard to preventing burnout resulting from everyday stressors (McGuinness, 2021).

As well as prevention, effective strategies for treating mental health conditions in autistic people are necessary. Previous research demonstrates the barriers that autistic people face in accessing adequate mental health care and recommends increased specialist training for healthcare professionals, client-led approaches and individualised accommodations and adaptations as needed (Adams & Young, 2021).

3.4.4 Strengths & limitations

The present study has both strengths and limitations, which should be considered when interpreting the findings. A key strength is the participatory approach, which involved autistic people from the outset in order to ensure that the findings are meaningful and important to the autistic community. Another strength is the mixed-methods design, which allowed for triangulation of data sources, facilitating richer and more reliable findings.

In terms of the limitations of the present study, the sample is not representative of the autistic population of Ireland as a whole, due to the exclusion of autistic people with a co-occurring ID. Furthermore, the number of trans participants in Phase 1 was higher than would be expected considering the general autistic population and convenience sampling involving advertising the study as related to ‘mental health and wellbeing’ may have attracted participants with an interest in mental health, rather than an accurate cross-section of the autistic population in Ireland. In addition, the participants were mostly recruited via social media advertising by AsIAm, which may have biased recruitment towards those who are at least somewhat interested in autism advocacy. In addition, the present study used measures developed for the neurotypical population, rather than measures developed specifically for autistic people. While this is common practice in the literature and allowed us to easily compare our findings to similar studies on the general population, it may have artificially inflated some scores due to overlapping features of mental health conditions and autism (e.g. poor sleep patterns).

Although we paid significant attention to recruiting a diverse sample of autistic participants, reaching marginalised sub-groups of the autistic population was a significant challenge. Thus, there is minimal ethnic diversity and a disproportionate number of participants in early to mid-adulthood, compared to mid to late-adulthood. In addition, the small sample of trans participants led to limited power in analysis and likely meant that potentially meaningful group differences were not identified.

One particular ethical consideration relates to the high levels of suicidal ideation identified in the present study, as over 50% of participants reported experiencing suicidal ideation on at least half of the days in the previous two weeks. While this figure is in line with current research (Hedley & Uljarević, 2018), it indicates a high level of potential risk involved when conducting research with this group. The present study provided contact information for helplines and advised potential participants not to take part if they felt their mental health might currently be vulnerable. Future research should ensure that these potential risks are carefully considered in advance of undertaking research with this group.

3.4.5 Conclusions & recommendations

The present study aimed to (1) explore the experiences and levels of mental health and wellbeing of a sample of autistic adults living in Ireland and (2) explore and understand the factors that contribute to the mental health and wellbeing of autistic people, according to autistic people themselves. High levels of depression and anxiety symptoms were identified in this sample of autistic adults based in Ireland, alongside low levels of reported mental wellbeing. Autistic women were at a heightened risk of anxiety, while autistic trans people reported more symptoms of depression (both compared to autistic men). Factors found to contribute to increased levels of mental health difficulties and poorer wellbeing were wide ranging, including suggested genetic predispositions, feelings of exclusion and isolation, childhood bullying, autism-related stigma and coping with the challenges of the neurotypical environment. Overall, our findings point to the need for increased inclusion and belonging for autistic people, as well as improvements in service provision for autistic people, in particular diagnostic services, peer support services and mental health services.

Chapter 4 – Discussion

There is clear evidence that autistic people experience more mental health difficulties than non-autistic individuals (e.g. Lai et al., 2019), but there is currently no consensus as to why this is the case. In order to develop effective prevention and treatment methods, it is essential to understand the factors at play (Mandy, 2022). The neurodiversity paradigm provides a framework for understanding autistic experiences, which considers both strengths and weaknesses, as well as the physical and social environment (Kapp, 2020). Through the lens of the neurodiversity paradigm, the present thesis aimed to gain an understanding of the factors that influence the mental health of autistic people without a co-occurring ID, from the perspective of autistic people. Autistic girls and women are an under-studied group, due to the historic and systemic biases against their identification, though there is considerable evidence that their presentation and experiences differ from their male counterparts (Hull et al., 2020). Thus, particular focus was placed on understanding the experiences of autistic females. Overall, this thesis aimed to address the following research questions:

- What is the existing evidence base of factors that contribute to the mental health, emotional wellbeing and social wellbeing of autistic women and adolescent girls, according to qualitative self-reports?
- What are the experience and levels of mental health difficulties and mental wellbeing of a mixed gender convenience sample of autistic adults in Ireland? Do these levels vary depending on gender?
- What factors contribute to the mental health and wellbeing of autistic adults in Ireland?

4.1 Current evidence of autistic females' perspectives on what influences their mental health and wellbeing

Chapter two systematically reviewed the available literature exploring factors that impact the mental health, emotional wellbeing and social wellbeing of autistic adolescent girls and women, according to qualitative self-reports. Findings provided insight into the key factors that have thus far been explored through qualitative means. A systematic screening process identified 41 studies that met the inclusion criteria, which included self-reports of 690 autistic girls and women (of which 253 were from online forums; Nagib et al., 2020) and contained discussion of factors that impacted their mental health, emotional wellbeing and social wellbeing. Studies most frequently explored university experiences (n = 5), general experiences and needs (n = 5) and masking (n = 4); only one study directly explored factors contributing to mental health (Halim et al., 2018). Studies were generally of high quality (26 high quality, 15 medium quality), perhaps owing to the inclusion criteria of publication in a peer-reviewed journal.

A process of thematic synthesis (Thomas & Harden, 2008) identified 9 main themes and 31 sub-themes where each theme described a factor (or multiple factors) that impact upon the mental health, emotional wellbeing an/ or social wellbeing of autistic adolescent girls and women. All themes and sub-themes fell under the over-arching theme of 'The Autistic Neurotype', which encompassed the biological and psychological aspects of being autistic, such as a preference for predictability and atypical sensory profiles. Moreover, each theme and sub-theme (with the exception of 'autism-centric mental health features') also fell under the over-arching themes of 'Stigma' and/ or 'The Neurotypical World'. That is, it was not that being autistic inevitably resulted in poorer mental health and wellbeing, but rather the stigmatisation of that identity and/ or interaction with various incompatible aspects of the neurotypical world that the synthesised studies suggested contributed to poorer mental health outcomes for autistic girls and women.

4.2 An investigation of factors impacting the mental health and wellbeing of autistic adults across all genders

Chapter three presented an empirical mixed-methods study of the factors that impacted the mental health and wellbeing of autistic adults across all genders. It also aimed to evaluate the mental health and wellbeing of the sample of autistic adults living in Ireland. It employed a sequential exploratory design. Phase 1 involved 20 autistic adults taking part in one-on-one interviews about their mental health experiences and their perspectives on the factors that impacted their mental health throughout life. Inductive thematic analysis was used to develop 6 themes and 16 sub-themes, which outlined an array of inter-connected factors reported to impact mental health and wellbeing. These included factors that are known to impact the mental health of the population as a whole, such as genetic predispositions, adverse life circumstances or events, social exclusion or isolation, and childhood bullying, as well as factors that are more specific to autistic people, namely autism-related stigma, the process of receiving a diagnosis of autism (or not) and the process of developing a personal identity as an autistic person.

Next, Phase 2 quantitatively examined some key factors identified within Phase 1 in a sample of 236 autistic adults living in Ireland. This phase of the study revealed that feelings of exclusion and isolation, as well as autism-related stigma were significant predictors of mental wellbeing, anxiety and depression. Having a positive view of one’s autistic identity was also associated with lower levels of depression. In addition, younger age was associated with higher levels of depression and lower levels of wellbeing, while being a cisgender female predicted higher levels of anxiety. Sense of belonging and inclusion, autism-related stigma and quality of autistic identity were consistently shown to be related to mental health and/ or wellbeing. A wider range of factors were also identified within the qualitative portion of the study, including suspected genetic predispositions, traumatic life experiences and challenges associated with the neurotypical environment (e.g. sensory environment).

4.3 Strengths & limitations

A key strength of the current thesis is the emphasis on placing autistic people at the centre of the process. This was achieved in numerous ways; within the systematic review presented in chapter 2 an autistic colleague completed the analysis and interpretation alongside me as a co-researcher, providing invaluable insights into autistic experiences. Moreover, the study focussed on collating lived experiences of autistic girls and women, which placed their experiences at the centre, rather than relying on proxy reports or quantitative data that may not represent the priorities and experiences of autistic females. The empirical study presented in chapter three was designed in collaboration with Ireland's national autism charity, utilised a consultation panel of nine autistic adults and also relied on the autistic participants themselves as experts in their own experiences, by directly asking them about their experiences that impacted their mental health. By placing autistic people at the centre of the research in the aforementioned ways, this thesis endeavoured to ensure that the outcomes are meaningful and important to the autistic community (Fletcher-Watson, 2019).

The mixed-methods sequential exploratory design of the empirical study presented in chapter three was another strength of the present thesis. This enabled the study to centre on the autistic experience and increase the richness of the findings through qualitative interviews, while also testing the generalizability of findings via quantitative investigation. This also allowed for integration of findings, facilitating deeper interpretation and more reliable findings.

The present thesis also has several limitations that should be considered when interpreting the findings. First, within Chapter two, gender is considered within a binary (male/ female) framework, which does not represent the full diversity within gender, especially within the autistic community (van der Miesen et al., 2018; Walsh et al., 2018). Particular attention was given to the trans community in Chapter three, but due to the limited sample size (n = 17) generalizability was limited. Other forms of diversity were also under-represented in chapter three, namely those in mid to late-adulthood and those of non-white backgrounds, therefore it is unknown if the findings are applicable to these sub-groups of autistic people. Finally, another significant limitation across both Chapter two and three was the lack of representation from autistic people with an ID (though this was not an exclusion criteria within chapter two, the majority of studies contained participants without a co-occurring ID). It is unclear what proportion of autistic people have a co-occurring ID, with a systematic review showing that estimates range from 13.3% to 84.4%. (Elsabbagh et al., 2012). Despite this uncertainty, they do conclude that evidence currently indicates that the frequency of an ID diagnosis is higher among the autistic population than in the population as a whole (Elsabbagh et al., 2012). Thus, the exclusion of this group in the present thesis limits the applicability of our findings. However, a co-occurring diagnosis of ID generally indicates different circumstances and experiences compared to those without an ID, thus research specifically designed to investigate the mental health of autistic adults with an ID may be best suited to address this gap.

4.5 Implications for practice & future research

Overall, this thesis provides a summary of factors that may impact the mental health of autistic people without co-occurring ID. Therefore, it may provide useful information to clinical psychologists completing psychological formulations with autistic people with mental health difficulties. Across Chapters two and three a clear over-arching theme of stigma can be identified. Goffman (1963) conceptualised stigma as the disjuncture between an individual's social identity and the idealised social norm. Indeed, this experience was often described by autistic people included in the present thesis, along with adverse consequences of this, including bullying, social exclusion, isolation and negative self-perception. Moreover, this stigma seemed to (consciously or unconsciously) trigger engagement in masking, in order to be accepted and not ostracised or victimised by neurotypical peers. Thus, promoting acceptance and reducing stigma against autistic people may serve to partially alleviate mental health concerns. Methods to achieve this may include autism acceptance training or anti-stigma interventions (e.g. Birnschein et al. (2021) and Jones et al. (2021)). While addressing stigma in this way has not traditionally been the role of a clinical psychologist, the field of community psychology has demonstrated how psychologists can work in partnership with particular communities to tackle injustices and inequalities that impact them with a view to improving mental health and wellbeing (BPS, 2018).

Themes of social connection and belonging were also common across Chapters two and three. There were also overlapping discussions of experiencing a sense of belonging and acceptance within the autistic community, while connecting with neurotypical people was challenging due to different communication styles, interests or activity preferences. As such, promoting opportunities for autistic people to connect with each other may be beneficial to mental health and wellbeing. The benefits of connecting with other members of the autistic community via organised peer support has been evidenced, for example via post-diagnostic support groups (Crompton et al., 2022). In addition, teaching non-autistic people about autistic styles of communication may also serve to break down barriers to meaningful social connection.

Experiences of victimisation and bullying were also common across both chapter two and three. Some individuals felt that they were at higher risk of victimisation due to being autistic. Often victimisation occurred within trusted relationships, thus providing autistic young people with training around indicators of ill-intent and features of abusive relationships may help them to identify and avoid these situations. One individual in Chapter two described her desire for such training, "*I think they've got to teach people who are the right people to go with… more skills on how to find the right sort of partner*" (Hannah, 2016, p. 3685). In relation to bullying, schools and workplaces must take responsibility for preventing bullying in these settings, as autistic individuals consistently described the negative impact on their mental health. However, the link between childhood bullying and mental health in adulthood was not corroborated by the quantitative findings, thus further research is necessary to understand the long-term implications of bullying during childhood (if any).

The process of discovering one's autistic identity and coming to accept and embrace this aspect of their identity was also a common discussion within both Chapters two and three. Given the positive experiences reported by individuals who received a diagnosis in adulthood, assessment and diagnostic services for adults should be available within public health systems, in order to reduce the barriers to accessing a diagnosis. In addition, findings of the present thesis suggest that these assessments should be completed in a way that promotes a positive autistic identity, for example clinical psychologists may consider adopting aspects of neurodiversity affirmative practices or strengths-informed assessment (Brown et al., 2021; Courchesne et al., 2015) in order to promote a positive autistic identity for their clients.

Another common topic across both chapters two and three was the challenges faced within a neurotypical world, for instance the sensory environment and unpredictable events or situations. Concepts of universal design may be helpful in addressing these adverse environments. Universal design suggests that designing environments in an accessible way by eliminating environmental barriers reaps benefits for both autistic individuals and others (Steinfeld & Maisel, 2012). Suggestions for universal design in the case of autistic people may include auditing and adapting the sensory environment and providing clear visual supports to improve predictability in the environment (Milton et al., 2016; Waisman et al., 2022). When working with autistic people, clinical psychologists could consider how the way in which they offer their services may be adapted to the needs and preferences of autistic people, in line with the principles of universal design.

A very wide range of factors that impact mental health and wellbeing were described in the present thesis. While we have quantified the impact of some key factors, these only accounted for a relatively small proportion of the outcomes studied. This highlights the need to conduct further research in order to understand the impact of the wide range of factors described by autistic individuals in the present thesis. This thesis may provide a reference point for future research, as it has described this issue from the perspective of the autistic individuals themselves, likely providing a useful and meaningful foundation for future investigations.

The present thesis adopted a neurodiversity affirmative approach, which impacted upon how the research was conducted, how the data were analysed and indeed the conclusions drawn. The neurodiversity paradigm offers an alternative view of autism compared to a traditional view of autism as a disorder and posits that autistic people are disabled by an interaction between their autistic traits and the environment. However, common cirticisms of this view should be borne in mind while interpreting the findings of the present thesis. For instance, many feel that the neurodiversity paradigm does not represent the experiences of people with ID and/ or higher support needs. The present thesis largely excluded autistic people with a co-occurring ID and thus it is not possible to conclude whether the neurodiversity affirmative approach would have been suitable to conducting research with this group.

4.6 Conclusion

Within this thesis a systematic review synthesised qualitative self-reports of autistic adolescent girls and women in relation to the factors that impact their mental health and wellbeing. This review suggested that being autistic does not necessarily have a direct impact on mental health and wellbeing, but rather their experiences are impacted by social factors related to stigma and the neurotypical environment. The empirical study integrated qualitative and quantitative data around experiences of mental health and the factors that impacted mental health and wellbeing to produce an overall understanding of how and why autistic people are more likely to develop difficulties with their mental health. Similar to the systematic review, it highlighted typical adverse events that autistic people may be at higher risk of, such as social exclusion, bullying and traumatic events, as well as experiences closely linked to being autistic, such as developing a positive autistic identity, experiencing autism-related stigma and challenges related to an unsuitable sensory environment. Taken together, these studies point to the need for increased inclusion and belonging for autistic people, particular community adaptations and a reduction in societal stigma against autistic people, as well as improvements in service provision for autistic people, in particular assessments with post-diagnostic supports that promote a positive autistic identity and the provision of opportunities for fostering social connections with other autistic people.

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Appendices

Appendix A: PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Introduction – aims & objectives
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Method - Eligibility criteria
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Method - Data sources and search strategy
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Method - Data sources and search strategy
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Method - screening & study

Section and Topic	Item #	Checklist item	Location where item is reported
			selection
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Method - data extraction and thematic synthesis
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Method - eligibility criteria
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Method - data extraction and thematic synthesis
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Method - data extraction and thematic synthesis
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Methods - data extraction and thematic

Section and Topic	Item #	Checklist item	Location where item is reported
			synthesis
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Methods- data extraction and thematic synthesis
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Results
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A
Study characteristics	17	Cite each included study and present its characteristics.	Results - overview table
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Results - table
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Results - table
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A

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

Appendix B: Data extraction form

Reviewer:	Date:
Authors:	Year:
Journal:	Country:
Study description Phenomena of interest	
Concepts related to current review Mental health – (details) Emotional wellbeing – Social wellbeing -	
Study design	
Study sample (sample size, age, gender, diagnosis)	
Sampling procedure	
Data collection procedure	
Data analysis methods	
Gender differentiated analysis	

Themes identified (underline those related to current review)

Appendix C. Quality Appraisal Checklist

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:

2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling,	Defensible Indefensible Not sure	Comments:

data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/ inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example:	Clearly described	Comments:

• Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Unclear Not described	
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method?	Reliable Unreliable Not sure	Comments:

• Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?		
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? For example: • How well are the contexts of the data described?	Rich Poor Not sure/not	Comments:

• Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	reported	
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example:	Convincing Not convincing	Comments:

• Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Not sure	
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:

13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration?	Appropriate Inappropriate Not sure/not	Comments:

• Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	reported	
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix E: Description of thematic synthesis (chapter 2)

Theme 1. Neurotypical & autistic mismatch

Subtheme: neurotypical & autistic mismatch creates barriers

Participants described that autistic and neurotypical communication styles are often incompatible and that misunderstandings are common as a result. This often created a barrier to communication between autistic and non-autistic people. For example, one participant described that placing a neurotypical lens on autistic communication can lead to erroneous meanings being interpreted.

> *“someone will start reading things into what I have said that I haven't said. Or I won't pick up on what someone else has implied and it just goes to hell, and the drama starts and it is just too much, and I just leave”* (Halim et al., 2018)

The women and girls also described a difficulty understanding the thoughts and feelings of neurotypical people, while others reports difficulty understanding instructions when neurotypical people do not describe them in enough detail. This even played out during childbirth:

> *“It was difficult, very difficult. I was doin’ the wrong thing or, um, when I was tryin’ to push, my doctor actually asked me, “Are you even pushing?” Like, I had no idea how to push, and he was just saying, “Just push towards your bottom.” Well, I had no idea what that meant, because it was vague, and I guess for other women they get that. But [not] for me.”* (Donovan et al., 2020)

Mismatches between autistic and neurotypical people were also reported to impact on social connections and thus social wellbeing. One reason for this was the aforementioned misunderstandings that develop between autistic and neurotypical people, which can cause both difficulty developing social connections with neurotypical people and give rise to conflict or problems within existing relationships.

> *"…he's realised now that a lot of the arguments we had were me misunderstanding what he'd said and him misunderstanding how I'd reacted."* (Leedham 2020)

There is also the mismatch in terms of interests and social preferences. For example, neurotypical people may have different interests or different requirements for friendships, such as needing very frequent contact, which some autistic women did not desire in a friendship.

> *"I'm happy having friends I only speak to once a year and I'm not sure if you ought to talk to them more often than that."* (Forster et al., 2020)

It was frequently noted that misunderstandings can have an impact on the emotional wellbeing of autistic girls and women. Participants described these misunderstandings as "exhausting" (Tierney et al., 2016) and "stressful" (Donovan et al., 2020), as well as reporting impacts on their self-esteem and mental health. These emotional reactions appeared to range from mild to severe.

> *"…neurotypical people… are a lot harder to read, and I don't feel relaxed"* (Crompton et al., 2020)

> *"Five participants had used self*-*harm as a way to cope with feelings associated with frequent rejections and miscommunications"* (Tierney et al., 2016)

Subtheme: Neurotypical social environment is troublesome

The participants indicated that the social environments typically created by neurotypical people were not comfortable for them, nor did neurotypical people make changes to make the environment more suitable. This included the physical or sensory environment, which could make an event completely inaccessible:

> *"The physical spaces we go to are extremely challenging. They often want to go to places that are busy or noisy"* (Crompton 2020)

The environments were also reported to be socially unequal, whereby the neurotypical people generally held the power and autistic people felt that they were in a social minority. This resulted in autistic people feeling under pressure to conform, rejected and even unsafe.

> *"It feels like in my classroom that I'm surrounded by lions… I feel like a mouse and everyone else is like a giant cat or something"* (Tierney 2016)

Subtheme: Neurotypical peers lack empathy

The autistic girls and women expressed a need to be better understood and felt that their neurotypical peers did not make efforts to understand them. Participants discussed the need for neurotypical people to understand a range of things about the autistic experience, including their functioning difficulties, communication styles, distress signals and sensory experiences.

> *"Neurotypical people do not get why certain things might be difficult or an issue for someone with autism. You try to explain it but they are constantly seeing it from a neurotypical perspective"* (Crompton et al., 2020)
>
> *"'And to a normal person it would just be "what is your problem?"… like "what makes you anxious about that? There is no reason to be anxious of*

> *that" when really, for someone who all their senses are heightened or not, that is terrifying"* (Robertson et al., 2018)

Subtheme: Ease with other autistics

Many women explained the ease of communication and interaction with other autistic people. This appeared to be a result of well-matched communication styles, feeling accepted, and the absence of strict social rules or expectations. Participants described increased authenticity and enjoyment, as well as decreased stress and exhaustion. (see also Theme 7, subtheme: 'Embracing the autistic community').

> *"with autistic people, who speak my language… it goes fantastically well most of the time"* (Livingston 2019)
>
> "*Whereas you start talking to autistic people and … they just know how it is, so going to socialise … is so much easier, because I know that … I can just get up and walk out and nobody is going to think anything about it"* (Robertson 2018)

Theme 2. Masking

Subtheme: Masking is essential in a neurotypical world

Many reasons for masking were discussed; together revealing that masking is seen as essential for autistic girls and women to survive in a neurotypical world. Women discussed a desire to "pass" as neurotypical in order to avoid standing out for being different. This seems to be an act of self-protection for many autistic women; an essential strategy to avoid bullying, discrimination and rejection (see also Theme 6: Victimisation & discrimination).

> "*When I was younger and more obviously odd and strange I was thought of as stupid and also badly physically and mentally bullied. I also lost employment. I want to avoid the bullying mostly. I have even been spat at in the street."* (Hull 2017)
>
> *"...some participants experienced inner conflicts, wanting to show their true selves, but being fearful of reactions"* (Leedham 2020)

It was also apparent that women must mask in order to succeed in a neurotypical world. For example, in order to make social connections with neurotypical people or to progress in their career.

> *"… fitting neurotypical peoples' interaction style (eg, eye-contact or small talk) was viewed as vital for achieving life goals (eg, independence and employment)" (Livingston 2019)*
>
> "*… Connections have to be made initially on neurotypical terms. Then, hopefully, on my terms as well*." (Hull 2017)

Subtheme: Negative emotional impact of masking

While autistic women reported that masking is essential for them to safely navigate their day-to-day lives in a neurotypical world, they also reported the serious impact on their mental health and wellbeing. Masking was described as a drain on psychological resources, as it requires concentration, constant self-monitoring and self-control. Girls and women described feeling "exhausted", "drained", "embarrassed", "unhappy", and "anxious" as a result of masking (Bernardin et al., 2021; Hull et al., 2018; Leedham et al., 2020; Tierney et al., 2016). Some participants even reported experiencing 'meltdown' after a period of masking.

> *"My head will be racing as if I'm interpreting another language. I will be incredibly anxious. It's like studying for an exam, constantly on edge trying to predict what others will say and do"* (Hull et al., 2017)

The autistic girls and women in these studies reported the huge strain that masking causes, because behaving in a neurotypical way will never feel effortless or natural to them. They go on to report that often their extensive efforts are still unsuccessful, compounding the negative emotional impact of masking.

> "*Learning how to be social doesn't make it easier or less stressful because it's still against my natural grain."* (Baldwin et al., 2016)
>
> *"However, the consequences of doing so were complex, with some feeling deeply unhappy and exhausted. In part, this was due to many attempts not appearing successful, leaving participants feeling on the periphery despite considerable efforts."* (Leedham et al., 2020)

Subtheme: Masking suppresses true self

Masking was also reported to have an impact on girls' and women's sense of self and authenticity. Participants reported feeling as though they were putting on a performance that diminished their true self and increased their stress levels.

> *"I think I had a sort of identity crisis really because I wasn't quite sure who I was anymore because I was so used to . . . pretending to be the same as everyone else when really I knew that I wasn't.*" (Tierney et al., 2016)
>
> *"Respondents often felt they were playing so many different roles, it was hard to keep track of their authentic sense of identity. This increased the anxiety and stress associated with camouflaging, as individuals lost a sense of grounding and security in who they were."* (Hull et al., 2017)

Masking also appeared to reduce authenticity in relationships, as participants felt that developing relationships through masking meant that they were based on deception and that their friends didn't truly get to know them. Although the girls and women reported that one of their reasons for masking was to build social relationships, due to the feeling that the relationships were inauthentic, their loneliness and isolation was perpetuated.

> *"That is the downside of* [masking]. *Having no true friends or having less true friends [...] you're basically changing who you are. So, you don't really know if you're friends with that person or not because they're not really being friends with you, they're being friends with the person you're changing to become."* (Bernardin et al., 2021)
>
> *"I feel sad because I feel like I haven't really related to the other people. It becomes very isolating because even when I'm with other people I feel like I've just been playing a part."* (Hull et al., 2017)

Subtheme: Dropping the mask

Girls and women discussed situations where they felt safe enough to drop their mask. Participants reported feeling comfortable to drop the mask when with other autistic people, as well as other trusted people and those with similar interests to them. (see also Theme 7, subtheme: 'Inclusive, accepting & supportive friendships' and Theme 8, subtheme: 'Others embracing my autistic self').

> *"Behaviours such as stimming, rocking and communicating in autistic ways were implicitly accepted by their autistic family and friends."* (Crompton et al., 2020)

> *"I think [we camouflage] because we don't feel too comfortable around certain people, and others we know well enough to trust. Ya know? We know them, we know we can trust them. [...] We know they're not someone who would scorn us for certain actions, they understand us."* (Bernardin et al., 2021)

They also explained how they managed their psychological resources by choosing when to mask and not mask. This included weighing up the social consequences in a particular situation and also changes across the lifespan, whereby older people felt less pressure to mask compared to those in adolescence.

> *"More generally, these pressures were greater when meeting new people, particularly those with good social skills, than with family and friends, and changed over the lifespan, being higher in adolescence and lower in older age."* (Livingston et al., 2018)

Subtheme: Benefits of masking

Some participants noted benefits associated with masking, specifically feelings of relief following 'successful' masking and that masking had afforded them success in a neurotypical world.

> *"With compensation, I have a job in which people respect my work and ask for my help and opinions…I am liked by my colleagues and friends…I haven't lived on the edge, lost and lonely, as I could have. I have been super super lucky.*" (Livingston et al., 2019)

Theme 3. Navigating social expectations

Subtheme: stress during social interactions

Women and girls often reported experiencing stress during social interactions. They reported fear of rejection, anxiety about upsetting others and worry about their ability to maintain conversations. Many reported that as a result they avoid social interactions, which in turn reduces the opportunities they have to develop desired social connections.

> *"It's just really hard for me to talk with kids my age because I just get worried that I'll be rejected. [...] Instead of talking to them and maybe risking them being mean to me, maybe I just don't say anything."* (Bernardin 2021)
>
> *"Most of the participants stated that meeting someone new for the first time was particularly hard for them: 'I don't like talking to new people as it makes me nervous. I generally try to avoid talking to new people if I can help it." (Forster et al., 2020)*

Some acknowledge that isolating themselves completely would be more comfortable, but that this would not be good for their wellbeing in the long term.

> *"I definitely couldn't be some kind of hermit. As much as I would like to be able to I don't think it would be good for me at all"* (Tierney et al., 2016)

Subtheme: Internalised ableism plays out in social interactions

Internalised ableism appears to emerge, both explicitly and implicitly, through participants' descriptions of the challenges that arise in social interactions. Some women and girls refer to themselves as the "problem" or report that they are ashamed or embarrassed of how they communicate and interact with others.

> *"I feel awkward and ashamed [when interacting with neurotypical people] . . . I still have a lot of internalised ableism about how I 'should' be able to do things that I find difficult."* (Crompton et al., 2020)
>
> *"despite my awareness, my ability to counteract my poor social skills lags behind. In short, now I know that I am the problem, but I still don't know how to fix myself very well.*" (Livingston et al., 2019)

Subtheme: The impact of neurotypical social norms

Neurotypical social norms were reported to impact on social interactions for autistic women and girls. The participants reported disliking these neurotypical social norms, as well as finding them difficult to understand and experiencing stress trying to keep up with them. (see also Theme 2: Masking)

> *"The worst thing is the constant requirement for social interaction with others and 'chit-chat'"* (Baldwin 2016)
>
> *"I hate it. I go over and over and over what they said and what I said. Did I understand them correctly, did I respond appropriately, did I make a gaffe? Have I offended anyone?"*

The pressure of conforming to these neurotypical social norms leads to participants feeling inadequate and reduces feelings of self-acceptance. They also create a barrier to developing social connections with others.

> *"making friends with people is harder than any person who wouldn't have it [autism] . . . Because there are all these rules."* (Cheak-Zamora et al., 2019)

Theme 4. Support & accommodations

Subtheme: Type of support & accommodations needed

The participants described the type of support that would be beneficial for both their social and emotional wellbeing. This included both education for the autistic girls and women themselves, as well as ways that the neurotypical systems (e.g. workplaces and healthcare settings) could adapt to accommodate their needs better. In relation to the former, they discussed skills training around coping with changes, explicit teaching on understanding neurotypical social skills and education on relationships and sex.

> *"I think they've got to teach people who are the right people to go with…. more skills on how to find the right sort of partner*." (Hannah et al., 2016)
>
> *"Melanie explained that the reason she wanted to have a face-to-face appointment was that "phone calls are difficult. I can do them, but it's just another stress area; I'm very stressed and I don't want to do extra stressful things"* (Rogers et al., 2017)

Participants also noted that they need autistic-led supports and/ or professionals that have a good understanding of autism to deliver the support required.

> *"In individual therapy, participants often described difficulties with emotion identification and their therapists' insensitivity or unawareness of these difficulties"* (Tint et al., 2018)

Women and girls described how functioning skills and the need for support varies significantly both within and between autistic people. They discussed a variety of things that impact functioning abilities, such as a change in routine, anxiety and the environment.

> “Through further thematic analysis of participants’ open comments, stress and anxiety were found to be common and debilitating factors across all areas of life addressed in the survey, including study, work and social interaction.” (Baldwin et al., 2016)

Subtheme: Stress about functioning difficulties

As well as anxiety impacting on functioning (as mentioned above), participants also reported that worrying about their functioning abilities creates further stress. Many girls and women expressed a desire to be independent, but recognised that they needed support.

> *“I’m getting really, really anxious and I’m worried that I won’t have the confidence and organisational skills to succeed. Just the thought of going back [*on practicum placement*] makes me feel sick. It’s exhausting.”* (Ward et al., 2018)

Subtheme: Barriers to accessing support

Various barriers to accessing the necessary supports were discussed by the girls and women in these studies, which included both systemic and personal barriers. A lack of timely diagnosis is one such systemic barrier that participants reported prevented them from accessing the support they needed.

> *“Saddened, too, for all the lost opportunities that would likely have come about had I known and received intervention and loving understanding as a child.”* (Lewis et al., 2016)

Women and girls also reported that when support was available, it was simply insufficient or only offered in crisis situations, rather than offered on an on-going basis in order to prevent crises from developing, meaning their mental health was impacted.

> *"In my experience, you cannot access help until you reach rock bottom. I was only able to get support when I had such crippling anxiety that I could not go shopping or even leave the house."* (Baldwin et al., 2016)

Individuals also faced personal barriers to accessing supports. Stigma related to being autistic or needing support was a barrier for some women, while others felt unworthy of support, feared that their requests would be rejected or had mental health difficulties that made it very difficult to seek support. Others masked their support needs or felt that they "should" be able to handle situations like their neurotypical peers do.

> *"Rochelle spoke about her apprehension towards making the initial confrontation to request academic support: I still get really, really nervous about talking to lecturers. I avoid asking because of this fear of rejection."* (Ward et al., 2018)
>
> *"When I was studying, I didn't think I was deserving of special treatment. I thought I should be able to handle it like everyone else. So what did I do? When I wrote my exams, I filed myself in with … 400 other people under blinking and blonking florescent lights."* (Tint et al., 2018)

Theme 5. Power of diagnosis

Subtheme: Diagnosis gives power back to the individual

Participants described how receiving a diagnosis of autism gave them back power, control and validation. They felt better able to advocate for their needs and it allowed them to develop new connections with others in the autistic community, as well as strengthen existing relationships with increased shared understanding.

> *"Self-awareness allowed participants to find understanding communities; strengthen relationships with new understanding"* (Moseley et al., 2020b)

Many girls and women discussed how diagnosis or self-identification of autism facilitated self-understanding, which brought a host of associated benefits for individuals' wellbeing and mental health through increased self-acceptance, coping skills and self-compassion. In many cases receiving a diagnosis allowed participants to make sense of their lives and the challenges they faced and to treat themselves with more compassion and less criticism.

> *"before, I wasn't diagnosed, and I think I just felt awful about myself and like 'why can't I cope with this' and it had a big toll on me mentally, whereas now, it's a lot easier and I sort of know now why things are the way [they are], and it's a lot easier to cope."* (Seers et al., 2021)
>
> *"I don't get as much anxiety as I used to … because I've got better understanding of – and because I understand it better I'm actually able to deal with it better … So I build strategies around that really."* (Leedham et al., 2020)

Subtheme: Missed & mis-diagnosis

Many girls and women reported receiving a diagnosis or self-identifying as autistic later in life, meaning they spent many years without the appropriate self-understanding or support. Strong emotional reactions to late diagnosis were common, with positive emotions commonly including “relief” and “elation”, largely for the reasons described above (Leedham et al., 2020). However, negative emotions also emerged, such as anger, sadness and outrage that they had not been identified as autistic much earlier in life.

> *“It has left me a little bereft of a life that could’ve been”* (Lewis et al., 2016)

Participants described how a lack of diagnosis had caused them significant struggling throughout life, including many developing mental health difficulties.

> *“I was exhausted trying to figure it out ... why things were so different for me, and ... by the time I had got to that diagnosis, I was already half dead, I was already in a functioning depressed state.”* (Leedham et al., 2020)

In the process of these struggles, some participants were diagnosed with mental health conditions, such as Obsessive Compulsive Disorder (OCD), Borderline Personality Disorder (BPD) or depression, and/ or other types of neurodivergence, such as Attention Deficit Hyperactivity Disorder (ADHD) or dyslexia. However, participants described how they never felt their experiences were fully explained, until they identified that they were autistic. Receiving incorrect or incomplete diagnoses created confusion and frustration for participants and also impacted the mental health support they were willing or able to access.

> *“[Clinician] would say ‘oh, you’ve got borderline personality disorder’ ... I explained to him exactly why I wasn’t BPD ... I wasn’t getting any answers, I just stopped going. I just stopped asking for help, I just stopped, you know, looking for answers.”*

Subtheme: External influences on the perception of the diagnosis

Despite the many benefits associated with diagnosis or self-identification, many participants experienced external factors that negatively impacted their perception of the diagnosis and thus their self-perception. Many participants discussed how autism is stigmatised and how others had a poor understanding of autism.

> *"Autism is stigmatized; society is not educated about it, often associates it to someone who is mentally retarded (forgive me for using this term), not able to function normally, and is disabled. The thought of being treated less then (sic) a normal human came to mind."* (Lewis et al., 2016)

Some participants also held these negative perceptions themselves and as a result struggled to accept that they were autistic. Others discussed how the intensive intervention that they received once they were diagnosed promoted the belief that their differences were a negative thing that needed to be changed.

> *"Kim explained that what came with the label, was intense, early intervention directed by a health professional. She experienced this 'sudden focus' on her as an effort to change her and frame her identity, in ways that, at that time, she did not understand"* (Mongensen et al., 2015)

Due to the stigma surrounding autism, participants worried about disclosing their autistic identity to those around them. Many girls and women did describe unhelpful or hurtful reactions to their disclosure of being autistic.

> "*I didn't want to tell them at first because I wanted them to have their own opinion before they find out something that could ... you know, let them treat me differently ... I didn't want to be perceived as different."* (Mongensen et al., 2015)

> *"… when I told my dad … he was … 'You don't have autism, you're perfect. There's nothing wrong with you' … he thinks I'm his perfect little girl … who's got nothing wrong with her, so I can't talk to him about if I've had a bad day." (Leedham et al, 2020)*

However, some also had positive experiences when they disclosed their diagnosis. These participants described feeling grateful that they can now be fully accepted for who they are and another experienced others being protective of her following the disclosure.

> *"One of the good things is that when you find out… when the people find out, sometimes they'll have… sometimes they'll like have your back a little bit more."* (Berkowitz et al., 2020)

Theme 6. Victimisation & discrimination

Subtheme: Bullied for being autistic

Many girls and women described bullying that was directly or indirectly connected to being autistic. Participants often reported that being 'different' was the reason that their peers victimised them, though they may or may not have been aware that their victim was autistic.

> *"When I was younger and more obviously odd and strange I was thought of as stupid and also badly physically and mentally bullied."* (Hull et al., 2017)

One participant reflected on the 'invisible' nature of her disability, as she felt that someone with a more visible disability would not have been victimised as she was.

> *"When asked whether those who bullied her knew that she had been diagnosed as having autism, she recalled how: 'Some of them did, some of*

> *them didn't, but even if they didn't, they still used to pick on me no matter what. .... 'cos they knew I was in [different class in school] but they would have changed if I was in a wheelchair, then they wouldn't have picked on me. I used to go home crying.'"* (Jones et al., 2013)

Participants described the negative emotional impact of this bullying and victimisation, which included anxiety and school absences.

> *"She also mentioned that her anxiety around peer interactions had recently resulted in her staying at home from school for two weeks as she was being bullied for having immature interests."* (Kelly et al., 2018)

Subtheme: Social othering & exclusion

As well as explicit bullying, many participants experienced exclusion from social groups and the experience of being 'othered' by their peers. Girls and women discussed both explicit exclusion from social groups and a general underlying feeling of being different or not being able to 'fit in'.

> *"Four of the seven participants responded that they had felt excluded from a group at some time, 'Yes, many times. Everyone has someone to talk to, they were laughing and joking around and honestly I didn't know what to do or say'" (Vine Foggo et al., 2017)*

One girl specifically described the additional challenge faced by autistic girls, due to the wider gap in social preferences and interests between them and their neurotypical counterparts:

> *"I think . . . it's probably harder for girls with Asperger's in a way than boys cos generally people socialise more with their own gender . . . being a boy*

> *with Asperger's you're probably more similar to neurotypical boys whereas an Asperger's girl is different to neurotypical girls."* (Tierney et al., 2016)

Subtheme: Vulnerability to abuse

Many participants reported experiencing abuse, largely reporting that this abuse was perpetrated by people who they believed to be their friends or partners. The abuse included sexual, financial and emotional abuse.

> *"I was really close friends with a girl but my dad pointed out that I kept doing things for her but I didn't see it. Like we'd go out for lunch and I'd pay and she wouldn't pay." (Kanfiszer et al., 2017)*

It appears as though autistic girls and women may be more vulnerable to such abuse than other groups due to difficulty recognising ill intent, which perpetrators take advantage of.

> *"Due to their inability to recognise others' intentions [autistic] participants worried about people taking advantage of them, or felt anxious about the unknown intentions of others"* (Halim et al., 2018)

Theme 7. Social connection

Subtheme: Need for inclusive, supportive & accepting others

Autistic girls and women spoke of their desire and need for social connections in life to ensure their social wellbeing. While many discussed having friendships and relationships that fulfilled this need, others discussed the challenges and effort associated with these relationships.

> *"This intrinsic motivation combined with experience of frequent peer rejection, sometimes stirred up ambivalent feelings about friendships; participants wanted friends, but had to go to great lengths to make and maintain friendships."* (Tierney et al., 2016)

Many girls and women discussed the importance of features such as inclusivity, support and acceptance within their social connections with others.

> *''I cant really remember, they are very accepting of me as i am, so it wasnt really a big thing to them. they found alternative ways for us to socialise i.e by comin to see me or doing things in their house where id feel more comfortable."* (Smith et al., 2013)

The participants often discussed finding these types of friendships in other autistic people, as well as in the LGBTQ+ community or in online communities. These types of friendships provided a great sense of belonging and joy to autistic girls and women and also promoted emotional wellbeing, as well as protecting them against negative emotional outcomes.

> *"Since getting autistic friends I think 'this is how neurotypical people must feel all the time' and that is quite sad actually. To realise that people have felt this their whole life, and at ease around people, and felt they belonged as much as I do now. It's a shame it didn't happen sooner."* (Crompton et al., 2020)

Subtheme: Facilitators of social connection

Participants discussed a variety of things that helped them to develop meaningful social connections with others. They mentioned friends and family members who value their personal qualities, such as honesty and sincerity:

> *"Friends often come to me to tell me their story. A lot of my friends say me that they talk to me easily because we can have an open conversation. I am free of bias, in the sense that I just honestly tell them the way things are. I do not beat around the bush, I am not unfriendly, just honest."* (Van Hees et al., 2015)

Many girls and women found social connections easier to establish in organised situations or when engaging in activities connected to one of their passionate interests. Examples included making friends at church, at work, when caring for animals or through clubs related to their passionate interests.

> *"*Mary explained that she was unable to make friends outside of work, but at work, she has friends because they are around horses […] "*…animals and horses, in general—they mean a lot to me, and they basically help me with my self-confidence and stuff."* (Cheak Zamora et al., 2020)

Some girls and women mentioned having close friends who would support them to integrate into the larger social group and help them to understand the neurotypical social rules at play.

> *"Through her I met other children in the neighborhood. For them I was a bit odd... they laughed with me but not at me. Biene made sure of this. Yes, I owe a lot to Biene!"* (Krieger et al., 2012)

Other factors that some participants mentioned were being part of the LGBTQ+ community and socialising with neurotypical boys, who had less strict social rules compared to neurotypical girls. Age was also mentioned, whereby in later life autistic women identified more suitable social environments and felt better able to navigate social situations.

> *"It does seem like there are disproportionately many queer people with ASD, and vice versa; autistic people who are queer. This may have helped me fit in with the community"* (Lewis et al., 2020)

Subtheme: Barriers to social connection

Many barriers to social connection (and thus social wellbeing) were also discussed by participants. A key barrier was the mis-match between autistic and neurotypical social and communication styles and preferences, which has been examined in a previous theme (see Theme 1, subtheme: *neurotypical & autistic mismatch creates barriers* for discussion of this). Aside from this, participants mentioned the additional difficulties associated with making friends in adulthood, without the support that is offered by the systems in childhood.

> *"they don't corral you as an adult," saying, as a child, "they put you into the public school system with a wide variety of personalities, which has the effects of making you get to know different people."* (Cheak Zamora et al., 2020)

Although some had mentioned the benefits of being a member if the LGBTQ+ community (see subtheme: Facilitators of social connection), some also described the additional challenges this brings.

> *"Despite the regular portrayal of both communities as very open-minded and accepting places, this has not been my experience. The LGBT community frequently ostracized me for being "weird" and I have found myself mistreated and bullied by other autistic people for being a lesbian—so I just don't really get involved in either."* (Lewis et al., 2020)

Lack of trust and anxiety were also mentioned as barriers to social connection. One participant described intense anxiety at the prospect of approaching someone to ask them on a date:

> *"The idea of dating is terrifying. I have trouble with the idea of approaching someone and asking them out, it's terrifying, I know that people do it everyday and it's not that big of deal but it immobilizes me"* (Lewis et al., 2020)

Theme 8. Embracing the autistic world

Subtheme: Embracing the autistic self

Participants discussed coming to a point of being able to accept themselves and take pride in their autistic identity. This appeared to have a positive effect on emotional wellbeing, as it was described as a liberating and powerful experience. They reported being most able to be their authentic selves when with trusted others (see also Theme 2, subtheme: Dropping the mask).

> "*I feel free, very much more free."* (Leedham et al., 2020)

There were also challenges with embracing their autistic selves, which were largely due to the negative external perceptions of others. This led to internal struggles for some women.

> *"I disregard other opinions on how a woman should appear, but at times I do resent that others might be thinking I don't dress or apply makeup in a suitable womanly way"* (Seers et al., 2021)

Subtheme: Embracing the autistic community

Many participants discussed how they embraced the autistic community and the many associated benefits of this for their social wellbeing. Girls and women experienced a sense of belonging, understanding and acceptance among their autistic peers. As a result they felt able to express their authentic selves, which was said to feel natural and validating.

> *"It's fab when we get together, autistic space is so validating compared with the outside world, it's wonderful to see people stimming away without feeling self-conscious."* (Crompton et al., 2020)

It was not only direct contact with other autistic people that was mentioned, even reading about the experiences of other autistic people induced a sense of belonging.

> *"I cried when I read (a book about [autism]) because I recognized myself in every paragraph"* (Lewis et al., 2016)

The autistic community was also emotionally supportive. Participants described how autistic peers shared coping strategies for mental health difficulties with each other or simply provided a safe space to discuss feelings.

> *"we still struggle in the same places and they've probably given me the most sort of ideas of what to do because we have all worked round stuff. 'Well this works for me, well this works for me.'... They really get it"* (Robertson et al., 2018)

Some participants stated that autistic spaces are simply essential for their wellbeing:

> *"It's very important to have autistic space for people . . . sometimes people fear this is a form of self silo-ing or segregation and I'm not trying to say we don't need to survive in the non-autistic world too . . . but it's such a lifeline for many of us"* (Crompton et al., 2020)

Subtheme: Others embracing my autistic self

Participants spoke of the desire to be accepted by others, without feeling like they need to alter themselves to achieve this. They also reported that feeling accepted by others would serve to reduce their anxiety.

> *"I want people to let me be. I've had all kinds of people who thought they were helping me stop doing things. I have been endlessly criticized about how different I looked, criticized about all kinds of tiny differences in my behavior. I wish they had accepted some of my behaviors I didn't have any control over."* (Robertson et al., 2018)

See also Theme 2, subtheme: 'Dropping the mask' and Theme 7, subtheme: 'Inclusive, supportive & accepting friendships' for more discussion on this topic.

Theme 9. Distinctly autistic experiences

Subtheme: Passionate interests

Passionate interests were reported to be beneficial to autistic girls and women in a variety of ways. Firstly, engaging in passionate interests promoted emotional wellbeing through eliciting feelings of joy, pride and freedom for girls and women. Participants also reported that being restricted from engaging with passionate interests would have a negative emotional impact on them.

> "She said that her interests – 'Do crafts, be an artist, read books, watch TV, play the computer and stuff' also made her feel good – 'free' and 'creative'." (Teti et al., 2016)

Passionate interests were also reported to facilitate social connections and learning.

> *"I know that they [an autistic person] might be telling me for 20minutes about some bird that they saw, but I know how they are feeling, because I feel happy when I see things that I like and I will go on about it. So even though I have no interest in what you are saying I understand how you feel."* (Crompton et al., 2020)

Participants also mentioned challenging aspects of having such passionate interests, which included the occurrence of burnout due to spending long periods of time focussed on a particular interest or activity. They also reported that their interests tended to differ to their neurotypical peers, which created a barrier between them and inhibited social wellbeing.

> *"Indeed, some reported that their strengths could be overbearing, and some became physically ill or withdrew due to overwork and stress."* (Anderson et al., 2020)

> *"... when I was at primary school I was very obsessed with windmills and no other kid ... shared my interest'. She poignantly described her experience of feeling different as an 'invisible glass barrier between me and them"* (Kanfiszer et al., 2017)

Subtheme: Predictability vs ambiguity

Ambiguity and unpredictability were reported to provoke stress and anxiety in the participants. This could include a last minute change of plans, a new environment, life transitions or indeed some social situations.

> *"People are very difficult because people are unpredictable." (Robertson et al., 2018)*

> *"It's about predictability, if I know what to expect then I find things easier"*

The inverse was also true, whereby many participants discussed that predictability and routine are good for emotional wellbeing, as they are calming and help them to cope.

> *"I've told my uni to tell me exactly when all my dates are for the next three years ... that helps me"* (Robertson et al., 2018)

On the other hand, participants also reported that transitions could be an exciting and fun time.

> *"Many participants used words like 'incredibly excited', 'happy', 'fun' and 'mostly optimistic' to describe the experience."* (Vincent et al., 2019)

Subtheme: Sensory experiences

Various types of sensory input and sensory overload were reported to have negative impacts, both emotionally and physically. Emotions mentioned included 'fear', 'anger', 'stress' and 'discomfort' (Robledo et al., 2012; Smith et al., 2013; Tierney et al., 2016). Some participants even reported experiencing shutdown or meltdown as a result of specific sensory experiences.

> *"Some sounds make me feel really bad in the pit of my stomach. I feel angry and aggressive and out of control; feeling aggressive towards someone who doesn't deserve it makes me feel guilty. I get very agitated. I may yell at people. My behaviour gets out of control. It can ruin my mood sometimes for*

> *days. The effects of the noise last much longer than the noise itself."* (Robledo et al., 2012)

Sensory inputs were also said to have physical effects on the participants, including pain, nausea and dizziness.

> *"I was really sensitive to everything and that was a huge stress cos [I] was like hurting physically as well . . . loud noises used to really scare me and hurt in my head."* (Tierney at el., 2016)

Sensory experiences also impacted on participants' social wellbeing, as they became a barrier to participating in some social activities where the sensory environment may trigger adverse reactions.

> *''I would make excuses to go outside, say i was hot, it was quieter in the night in town, but very soon i would just not go to clubs pubs etc. i felt like i didnt have a choice it was just too painful to stay.''* (Smith et al., 2013)

In addition, aversion to some sensory experiences created difficulties in relationships as it made physical closeness very challenging.

> *"I also find it challenging when some of my sensory issues raise their heads. Some thing just gross me out, and it sucked when I was dating a girl and her touching me—even leaning against me—set of my sensory issues regarding hygiene and other people's icky body stuff touching me…"* (Lewis et al., 2020)

However, sensory experiences could also have a positive impact on emotional wellbeing, as certain types of sensory input was reported to be calming for participants.

> *‘‘my tai chi teacher was experimenting on me one evening and i realised that being squeezed is very comforting’’* (Smith et al., 2013)

Subtheme: autism-centric features of mental health difficulties

Some girls and women discussed features of mental health difficulties that were closely linked to having an autistic neurotype. These included cognitive features, such as “obsessive tendencies” associated with OCD (Badlwin et al., 2016) and having more ‘literal’ cognitive styles that contribute to disordered eating habits.

> *“We’re all so literal, and all these messages that are out there and all these skinny girls on Instagram- now it’s the bodybuilders on Instagram, you know, the fitness freaks on Instagram. . . I think these things are all around us, I think we’ve got to think about them very clearly and carefully. Particularly when we’re thinking about how literal autistic people take these messages”* (Kinnaird et al., 2019)

The experience of ‘alexithymia’ was also mentioned, which is a difficulty in experiencing, recognising and expressing emotional states.

> *“Challenges with identifying their own emotions were also discussed by participants. Geneva spoke extensively of this.”* (Robledo et al., 2012)

Meltdown and shutdown were also discussed. These were both described as responses to overwhelming demands in the environment, where ‘meltdown’ is an external expression of distress, which may include self-injurious behaviour, and ‘shutdown’ is an experience of feeling excessively tired and unable to actively respond to the situation, leading to complete withdrawal.

"Audrey explains a process where mental processing capacity is exceeded, sensory overload may occur and anxiety is then present as described earlier, this becomes too difficult to deal with and rest and withdrawal is needed (shutdown). If shutdown is prevented the consequence is a meltdown, which may include self-injurious behaviours, as the person is no longer able to deal with the situation." (Halim et al., 2018)

Appendix F. Five finger decision making

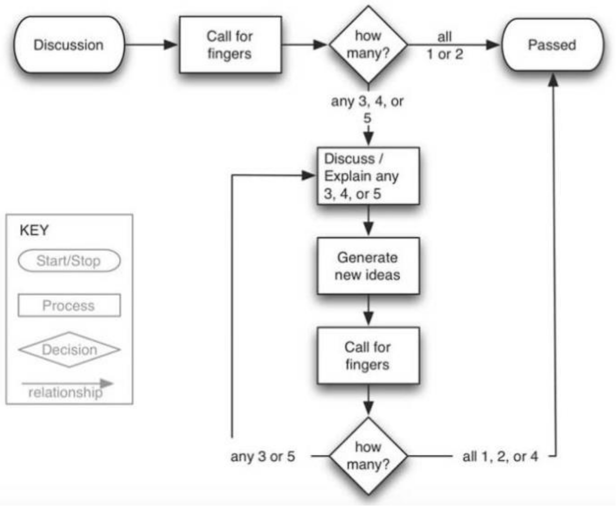
One Finger -- Yay, I approve! Do it!

Two Fingers -- Meh, I'm not thrilled, but I'll approve.

Three Fingers -- I am not sure, I need more information or discussion.

Four Fingers -- I don't like it, I won't approve it, but I can live with it.

Five Fingers -- I hate this so much that I can't live with having my name associated with it.



Appendix G. Template for discussion among consultation panel

Read through the extracts from the interviews and discuss the following questions. One person in the group should note down the key points from the group's discussion, including the responses to the questions below.

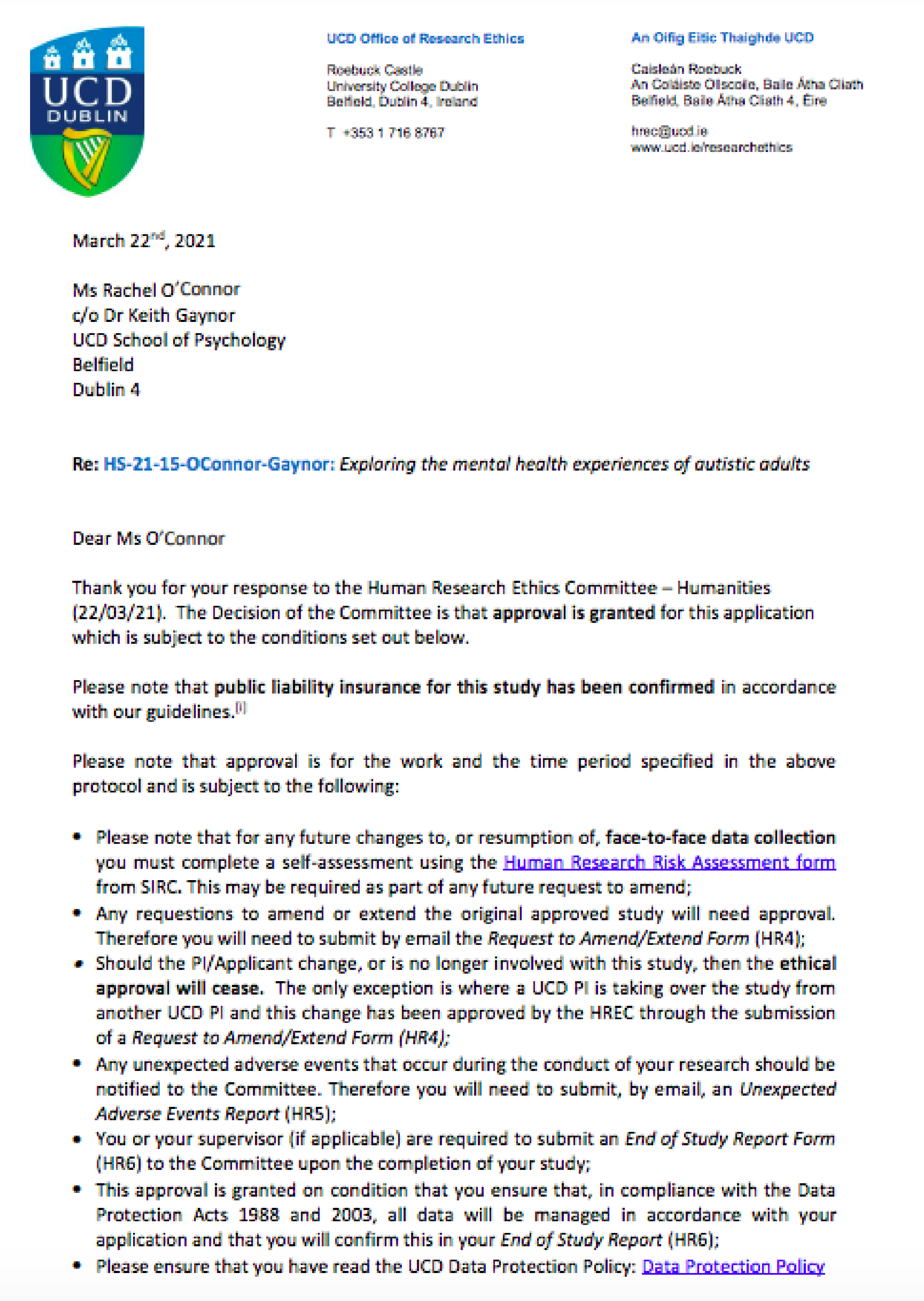
1. What key factor(s) is/ are being discussed by participants in the extracts? What overall title would you give this/ these factor(s)? This may be one word or a short phrase. (e.g. 'work related stress' or 'stigma')

2. How did this factor impact the mental health or wellbeing of the participants?

3. What are the similarities and differences between the interviewees' experiences of this factor?

4. Based on the extracts you have read, summarise in a few sentences/ bullet points how this factor impacts autistic people's mental health.

Appendix H. Ethical approval letter



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March 22nd, 2021

Ms Rachel O'Connor
c/o Dr Keith Gaynor
UCD School of Psychology
Belfield
Dublin 4

Re: HS-21-15-OConnor-Gaynor: *Exploring the mental health experiences of autistic adults*

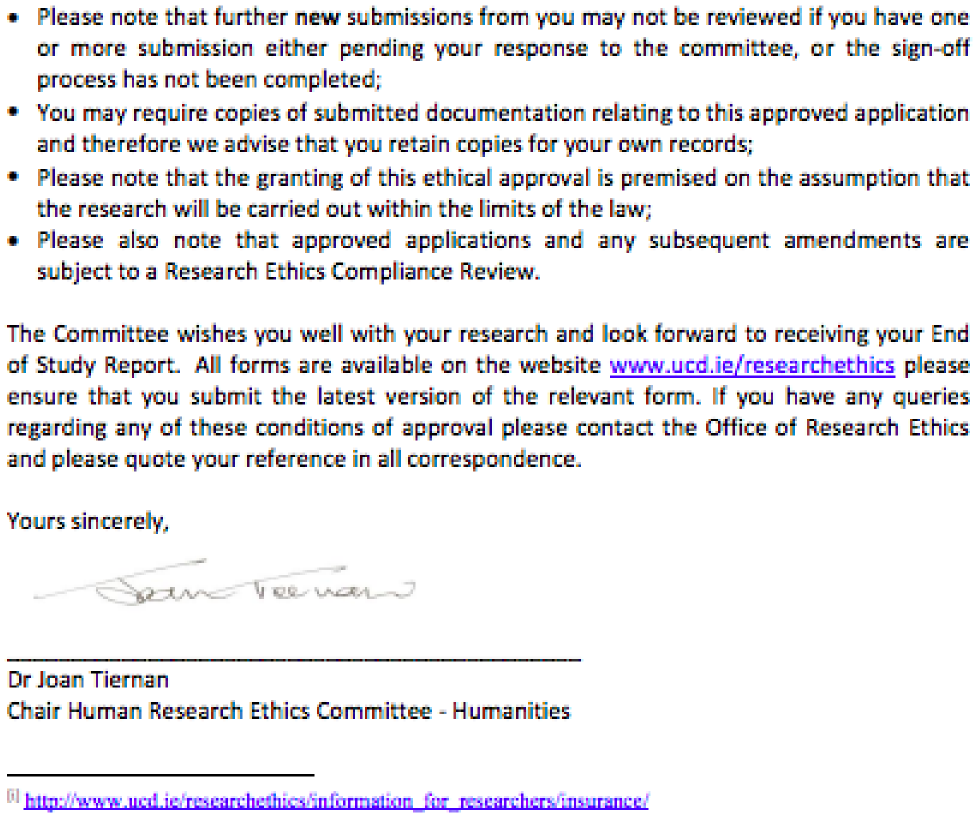
Dear Ms O'Connor

Thank you for your response to the Human Research Ethics Committee – Humanities (22/03/21). The Decision of the Committee is that **approval is granted** for this application which is subject to the conditions set out below.

Please note that **public liability insurance for this study has been confirmed** in accordance with our guidelines.[i]

Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:

- Please note that for any future changes to, or resumption of, **face-to-face data collection** you must complete a self-assessment using the Human Research Risk Assessment form from SIRC. This may be required as part of any future request to amend;
- Any requestions to amend or extend the original approved study will need approval. Therefore you will need to submit by email the *Request to Amend/Extend Form* (HR4);
- Should the PI/Applicant change, or is no longer involved with this study, then the **ethical approval will cease.** The only exception is where a UCD PI is taking over the study from another UCD PI and this change has been approved by the HREC through the submission of a *Request to Amend/Extend Form (HR4);*
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to submit, by email, an *Unexpected Adverse Events Report* (HR5);
- You or your supervisor (if applicable) are required to submit an *End of Study Report Form* (HR6) to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data Protection Acts 1988 and 2003, all data will be managed in accordance with your application and that you will confirm this in your *End of Study Report* (HR6);
- Please ensure that you have read the UCD Data Protection Policy: Data Protection Policy



- Please note that further **new** submissions from you may not be reviewed if you have one or more submission either pending your response to the committee, or the sign-off process has not been completed;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;
- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;
- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website www.ucd.ie/researchethics please ensure that you submit the latest version of the relevant form. If you have any queries regarding any of these conditions of approval please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely,

____

Dr Joan Tiernan
Chair Human Research Ethics Committee - Humanities

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[i] http://www.ucd.ie/researchethics/information_for_researchers/insurance/

Appendix I. Phase 1 information sheet

Information sheet

Study title: Exploring the mental health experiences of autistic adults in Ireland.

Ms. Rachel O'Connor (Trainee Clinical Psychologist, School of Psychology, UCD) is the main researcher of this study. This study has been co-designed by Rachel, Gaibhin McGranaghan (Policy Officer, AsIAm) and a panel of seven autistic adults from various backgrounds. The panel will continue to work on the project, advising Rachel and Gaibhin on the interpretation and dissemination of findings.

What is this research about?

We would like to better understand what factors impact negative and positive mental health for autistic adults. We would also like to understand autistic adults' experiences of accessing mental health support.

Why am I doing this research?

We hope the findings of this research project will produce a set of recommendations on how to reduce mental health difficulties in the autistic population in Ireland. We would also like to understand if and how autistic people access mental health supports in Ireland at the moment, so that we can advise on how the system could be made more accessible to autistic adults.

Why have you been invited to take part?

You have been invited to take part because you identify as an autistic adult. That is, you have a formal diagnosis of autism (or Autism Spectrum Disorder, Asperger's Syndrome, or Pervasive Developmental Delay) or self-identify as autistic. You must also:

- Be 18 years old or above.
- Not have an intellectual disability.
- Have some experience of mental health difficulties (in your own opinion) – this may be very mild or very severe. You do not need a formal diagnosis of any mental health condition and you may or may not have received support in the past or present.
- Be living in Ireland.

How will your data be used?

All individual information collected will be anonymised following the interview. This means that if you choose an oral interview your interview will be audio recorded and transcribed (by one of our two Research Assistants) and then all information that could potentially identify you will be removed from this transcription. The original audio recording will be stored on a password-protected hard drive until this research project is completed. If you choose a written interview, this text will be copied into a word document and then all information that could potentially identify you will be removed from this document. Your original messages will be deleted once this process is complete.

You will generate a unique code under which all of your anonymised data will be stored. This may be used to link your demographic information to your interview and any future phases of the research study that you may decide to participate in, to facilitate analysis.

Your anonymised data will be archived for 10 years following the completion of this project. This data will only be accessible to the UCD researchers listed at the bottom of this information sheet.

The resulting cumulative findings will be used for research articles, conference presentations, policy recommendation reports and other dissemination activities in order to share our findings with others. Anonymised information and quotes from your interview may be used in these.

Your email address will only be used for the purposes that you specifically consent to. For example, you will be asked if you would like to be contacted for future phases of this research project and if you agree to this your email address will be securely stored and you will be contacted for this purpose only.

What will happen if you decide to take part in this research study?

Your participation in this research is completely voluntary. [repetition deleted] If you would like to participate, this will involve taking part in an interview with either Rachel O'Connor (UCD) or Gaibhin MacGranaghan (AsIAm). This will be arranged as follows:

1. Finish completing this survey by reading this information sheet, completing the consent form (on the next page) and then complete a survey about yourself.
2. Rachel or Gaibhin will contact you via your preferred email address to arrange your interview and you will be provided with further information about the interview at this time, including the interview questions.
3. You will be asked to choose how you would like to take part in the interview:
    - Zoom one-on-one informal verbal interview
    - Zoom one-on-one informal interview using the chat function
    - Responding to open-ended questions in an online survey & subsequently responding to follow-up questions via email
4. You will be offered other accommodations if needed, such as
    - Having a support person with you at the interview
    - Breaking up the interview into shorter sessions
    - Adaptions to the sensory environment

If the above options do not suit your needs, please get in touch with us and we will do our best to accommodate you.

How will your privacy be protected?

Everything that you discuss in your interview will remain confidential and will only be heard/ seen by the interviewer and the transcriber (a Research Assistant). Following this only an anoymised version of your transcribed interview will be retained (responses via survey/ email/ audio recording of oral interview will be deleted when the research project is complete). At all times your private data will be stored securely within password-protected files and will be backed up on an encrypted hard drive. Only anonymised data will be stored on a laptop and UCD Google Drive, to which only the lead researcher will have on-going access.

Are there any benefits of taking part in this research study?
Benefits include the opportunity to share your experiences of mental health and wellbeing as an autistic adult in Ireland, to have your voice and to impact system change. This study aims to improve the mental health services that autistic adults receive in Ireland and also to provide evidence for reasonable accommodations and adaptations in communities that may help improve the mental health and wellbeing of autistic people.

Are there any risks of taking part in this research study?
This study has been co-designed with a panel of autistic adults. The panel members have lent their expertise in how we can conduct this research in a way that is comfortable and enjoyable for participants. As such, we have minimised any possibilities for distress or discomfort throughout the research process.
This being said, there is still a possibility that discussing your own experiences of mental health may be distressing. If you think discussing these sensitive topics may be distressing for you, we advise you not to participate at this time. If you decide to take part and become distressed during or after the interview, you may consider reaching out to one of the support organisations listed at the bottom of this page. You can also stop the interview at any time and withdraw from the study at any stage.

Can you change your mind at any stage and withdraw from the study?
You can withdraw from the study without explanation or warning at any point until two weeks after you complete the interview. If you withdraw we will permanently delete your interview recording and transcript.

How will you find out what happens with this project?
If you would like to receive a summary of the findings of this research study upon its completion, please tick the relevant box on the consent form. Alternatively, we will be sharing our findings in various formats on the AsIAm website and social media, so you can check the AsIAm website for any updates (ww.asiam.ie).

Support services: The subject matter of this study (mental health experiences) can be a distressing topic. If you feel this will be too distressing for you at the moment, please consider not taking part at this time. If you require any information or support after engaging in your interview, these are contacts of services that could help:

- HSE *text-based* mental health service: Text HELLO to 50808
- Samaritans *phone line* for mental health support: Call 116123

Contact details for further information
If you have any questions about the research, please contact Rachel before continuing with this survey. You can leave this survey and return to it via the same link at any time. You can contact Rachel via email:
Rachel O'Connor (main researcher, UCD): rachel.o-connor@ucdconnect.ie

Gaibhin McGranaghan is a co-researcher on this project and a Policy Officer at AsIAm. If you would like to contact him you can do so on gaibhin@asiam.ie

Dr. Keith Gaynor is supervising this research project. If you would like to contact him, you can do so on keith.gaynor@ucd.ie

Appendix J. Phase 1 consent form

Consent form

Study title: Exploring the mental health experiences of autistic adults in Ireland.

Please select either 'yes' or 'no' for the following items:

	Yes	**No**
I have read and understood the information sheet about this research study.	☐	☐
I have had opportunity to ask questions and any questions I had have been answered fully and to my satisfaction.	☐	☐
I understand that I do not have to take part in this study if I do not want to and I can opt out at any time without reason.	☐	☐
I understand that my data will be anonymised and stored securely in a password-protected file on a laptop, on an encrypted hard-drive and within UCD Google Drive until this study is complete.	☐	☐
I understand that that my anonymised data will be archived for 10 years following the completion of the study and that this will <u>not</u> be shared with anyone outside the research team.	☐	☐
I understand that in any reports on the findings of this study my identity will remain anonymous, including in quotations.	☐	☐
I give consent for my interview to be recorded and I understand that this recording will be destroyed once this research is finished.	☐	☐
I would like to be contacted about the next phase of this research project (an online questionnaire). If yes, the email address you provide will be stored and used for this purpose.	☐	☐
I would like to be provided with a summary of the findings of this research study upon its completion. If yes, the email address you provide will be stored and used for this purpose.	☐	☐

Email address: ____
(optional)

Clicking 'next' confirms your consent to the items above for which you selected 'yes'

Appendix K. Demographic survey for Phase 1 and 2

In order to link this questionnaire with your interview (and any future parts of the study you may choose to take part in), we ask you to create a unique participant code, as follows:

What day of the month is your birthday? _____
What are the last 4 digits of your phone number? ________
What is the first letter of your middle name? (if none, use x) ______

For example, my birthday is the 19th of February (19), my phone number is 0870575161 (5161) and my middle name is Ann (a). Therefore, my code is 195161a.

Please enter your code here: _______

Do you have a formal diagnosis or self-identify as having an Autism Spectrum Condition (ASC)? These include autism/ autism spectrum disorder (ASD)/ Asperger's Syndrome, Pervasive Developmental Delay (PDD), or PDD-Not Otherwise Specified (PDD-NOS)?
Yes, formal diagnosis (continue to next question)
Yes, self-identified (skip to question Y)
No (skip to question X)

If formally diagnosed, how old were you when you received a diagnosis? ______

Did you suspect you were autistic prior to receiving a diagnosis?
Yes
No
not sure

If yes, how old were you when you began to suspect that you may be autistic? ________

Y. If self-identified, how old were you when you became certain that you are autistic? ________

When discussing your autism diagnosis, which terminology do you prefer?
Identity first (i.e. autistic person)
Person first (i.e. person with autism)
Person on the spectrum
No preference
Other (please specify: ______________)

X. What is your date of birth? (DD/MM/YYY) ___/_____/_________

What is your gender?
Male
Female
Non-binary

Agender
Other (please specify: ______________)
Prefer not to say

Do you identify as transgender?
Yes
No

Do you consider yourself to be:
Heterosexual
Homosexual
Bisexual
Other (please specify: _____________)
Prefer not to say

Do you consider yourself to be:
White Irish
White (other)
Irish travelling community
Asian (including asian Irish)
Black (including black Irish)
Other (please specify: ________)

What mode of communication do you use most when interacting with others?
Oral communication (speaking)
Picture Communication system
Sign language
Augmentative and Alternative Communication (ACC) device
Other (please specify: __________________)

Not including autism, do you have any (other) neuro-developmental conditions (e.g. ADHD) or any mental health conditions (e.g. Generalised Anxiety Disorder)?
yes
no

If so, what (co-occurring) conditions do you have? Please <u>tick</u> (✓) as appropriate.

Condition	Do you have this?		Type of diagnosis	
	Yes	No	Formal diagnosis	Self-identify
ADHD (Attention Deficit Hyperactivity Disorder)				
Dyslexia				
Developmental Language Disorder (DLD) (previously: Specific Language Impairment)				
Developmental Coordination Disorder (DCD) (previously: Dyspraxia)				

Intellectual Disability (ID) (previously: Learning Disability)				
Depression				
Anxiety Disorder				
Obsessive Compulsive Disorder (OCD)				
Post-traumatic Stress Disorder (PTSD)				
Other (please specify: ________________)				

Have you ever received professional support for your mental health? (e.g. from a psychologist, psychiatrist, counsellor, therapist, etc.)
Yes
No

If so, was this through the public service (e.g. HSE) or a private provider?
Public
Private
Both
Other (e.g. charity)

What is your highest level of education achieved:
Junior Certificate
Leaving Certificate
Bachelor Degree (QQI level 7 or 8)
Post-graduate degree (QQI level 9 or 10)

What is your current employment status (if your employment has been impacted by COVID-19, please select your employment status prior to COVID-19):
Employed full-time
Employed part-time
Unemployed
Self-employed
Student
Retired
Unable to work

What is your living situation:
Living alone (independently)
Living with a partner (with or without children)
Living with your child(ren) (without a partner)
Living with family members (e.g. parents, sibling)
Living with friends/ house-mates
Living in supported accommodation
Other (please specify: ______________)

What is the annual income of your household?

Under €20,000
€20,001 - €40,000
€40,001 - €60,000
€60,001 - €80,000
€80,001 - €100,000
€100,001 +

Which best describes the kind of area you live in?
City centre
Suburbs
Town
Village
Rural

Appendix L. Interview schedule

General guidelines

Use open questions & allow the participant time and space to answer in their own words

When asking follow up questions, use the same language that the participants use when describing their experiences. If you are not sure what the participant means by something they say, ask them to clarify this.

Elicit unique participant code:

1. What day of the month is your birthday? ________
2. What are the last 4 digits of your phone number? _________
3. What is the first letter of your middle name? ________ (if none, use X)

Participant code: ____________________

Agree on signals for potential distress

Script: Some of the topics we will be talking about may be upsetting or distressing. Please feel free to stop, pause or slow down the interview at any time. Are you comfortable communicating these requests verbally? Or would it be helpful for you to have non-verbal signal to stop, pause or slow down the interview?

Discuss preferred non-verbal signals, where desired.

Examples:

Hand signals

Holding up a nearby item (pen, post-it note)

Other as suggested by participant

Main questions	**Follow up questions**
Can you tell me about any experiences you have had with mental health difficulties?	
Please tell me about some things that have negatively impacted on your mental health throughout your life? You have mentioned [factors] so far, is there anything else you want to mention before we move on?	You mentioned [factor] impacted on your mental health, can you tell me more about this? How was it exactly that [factor] impacted your mental health?
Please tell me about some things that have protected your mental health or wellbeing throughout your life? You have mentioned [factors] so far, is there anything else you want to mention before we move on?	
Did you seek professional support for these difficulties?	If yes Can you tell me a bit about your experience of

	seeking support? What do you feel helped you throughout this process/ made this process easier? What made this process difficult? Did you manage to access mental health support in the end?
	If no Why not? [What made it difficult to seek support?] How did you cope? Did this have any implications on your life?
If they received MH support Can you tell me about your experiences of getting MH supports as an autistic adult?	What were the good things about it? What could be improved?
Did the healthcare professionals you came into contact with have knowledge and understanding of autism?	How did this impact the process of seeking support (positively/ negatively)? How did this impact the care you received (positively/ negatively)?
What were the location and environment like where you received support?	
What recommendations would you give to MH services in order to better support autistic people?	Can you tell me more about that? What would that look like? How might this help autistic people? How might services go about that?

Appendix M. Phase 2 information sheet

Study title: Exploring the mental health experiences of autistic adults in Ireland.

Ms. Rachel O'Connor (Trainee Clinical Psychologist, School of Psychology, UCD) is the main researcher of this study. This study has been co-designed by Rachel, Gaibhin McGranaghan (Policy Officer, AsIam) and a panel of seven autistic adults from various backgrounds. The panel will continue to work on the project, advising Rachel on the interpretation and dissemination of findings.

What is this research about?

We would like to better understand why autistic adults experience more mental health difficulties than the non-autistic population. In the first part of this study, we conducted interviews with 20 autistic adults about their experiences of mental health difficulties. Based on what they told us, we identified several factors that may impact on autistic people's mental health. This part of the study is a survey, which will ask questions about these factors that we identified, as well as your wellbeing and mental health.
This survey will take approximately 20 minutes to complete.

Why am I doing this research?

We are doing this research to understand the mental health experiences of autistic adults in Ireland. We hope the findings of this research project will produce a set of recommendations on how to reduce mental health difficulties in the autistic population in Ireland.

Why have you been invited to take part?

You have been invited to take part because you identify as an autistic adult. That is, you have a formal diagnosis of autism (or Autism Spectrum Disorder, Asperger's Syndrome, or Pervasive Developmental Delay) or self-identify as autistic. You must also:

- Be 18 years old or above.
- Not have an intellectual disability.

How will your data be used?

All data we collect will be anonymous, meaning you will not be identifiable from the data we collect. We will never ask you for your name. Instead, you will generate a unique code under which all of your anonymous data will be stored. This may be used to link this survey to any previous phases of the research study that took part in (if applicable) to facilitate analysis.

The resulting cumulative findings will be used for research articles, conference presentations, policy recommendation reports and other dissemination activities in order to share our findings with others. Your anonymous data will be archived for at least 10 years following the completion on this study. This data will be freely available to other researchers, who may use it to verify our findings, replicate this study or conduct a meta-analysis (combining many different research studies on the same topic to better understand this particular topic).

What will happen if you decide to take part in this research study?

Your participation in this research is completely voluntary. After reading this information sheet, you can continue to the next page of this survey, which is the consent form. If you give your consent to participate, several questionnaires will be displayed on the following pages for you to complete. These questionnaires will consist of multiple-choice questions and you will be asked to select the answer to each question that best applies to you. In total, these questionnaires will take you approximately 20 minutes to complete.

How will your privacy be protected?

All data collected will be anonymous, so it will not be possible for the researchers to identify you. At all times your anonymous data will be stored securely within a password-protected file and will be backed up on an encrypted hard drive and UCD Google Drive, to which only the lead researcher will have on-going access.

Are there any benefits of taking part in this research study?

Benefits include the opportunity impact system change with regard to autistic mental health in Ireland. This study aims to improve the mental health services that autistic adults receive in Ireland and also to provide evidence for reasonable accommodations and adaptations in communities that may help improve the mental health and wellbeing of autistic people.

Are there any risks of taking part in this research study?

This study has been co-designed with a panel of autistic adults. The panel members have lent their expertise in how we can conduct this research in a way that is comfortable and enjoyable for participants. As such, we have minimised any possibilities for distress or discomfort throughout the research process.

This being said, there is still a possibility that answering questions about your mental health may be distressing. If you think answering questions on these sensitive topics may be distressing for you, we advise you not to participate at this time. If you decide to take part and become distressed during or after the survey, you may consider reaching out to one of the support organisations listed at the bottom of this information sheet. You can also stop the survey at any time by closing the page on your Internet browser.

Can you change your mind at any stage and withdraw from the study?

You can withdraw from the study without explanation or warning at any point until before you submit the survey. You can leave the study by simply closing the survey page on your Internet browser. If you withdraw we will permanently delete any data that you have provided. Once you have submitted the online survey, you will no longer be able to withdraw from the study.

How will you find out what happens with this project?

All information and findings related to this project, including with reports and articles, will be available on the AsIAm website as they become available (www.asiam.ie).

Support services: The subject matter of this study (mental health experiences) can be a distressing topic. If you require any information or support after engaging in the survey, these are services that could help:

- HSE *text-based* mental health service: Text HELLO to 50808
- Samaritans *phone line* for mental health support: Call 116123

Contact details for further information

If you have any questions about the research, please contact Rachel before continuing with this survey. You can leave this survey and return to it via the same link at any time. You can contact Rachel via email with your questions:

Rachel O’Connor (main researcher, UCD): rachel.o-connor@ucdconnect.ie

Adrian Carrol is a co-researcher on this project and a Policy Officer at AsIAm. If you would like to contact him you can do so on adrian@asiam.ie

Dr. Keith Gaynor is supervising this research project. If you would like to contact him, you can do so on keith.gaynor@ucd.ie

Appendix N. Consent for for Phase 2

Study title: Exploring the mental health experiences of autistic adults in Ireland.

Please select either 'yes' or 'no' for the following items:

	Yes	**No**
I have read and understood the information sheet about this research study.	☐	☐
I have had opportunity to ask questions and any questions I had have been answered fully and to my satisfaction.	☐	☐
I understand that I do not have to take part in this study if I do not want to and I can opt out at any time without reason.	☐	☐
I understand that my data will remain anonymous and stored securely in a password-protected file on a laptop, on an encrypted hard-drive and within UCD Google Drive until this study is complete.	☐	☐
I understand that that my anonymous data will be archived for 10 years following the completion of the study and that this will be freely available to other researchers.	☐	☐
I understand that in any reports on the findings of this study my identity will remain anonymous.	☐	☐

Clicking 'next' confirms your consent to the items above for which you selected 'yes'

Appendix O. Questionnaires included in quantitative survey Phase 2

Positive wellbeing: Warwick-Edinburgh mental wellbeing scale (WEMWBS; Tennant et al., 2007)

Below are some statements about feelings and thoughts. Please select the responses that best describe your experience over the last 2 weeks.
[Participants rate on scale from 1 – 5. 1 = none of the time, 2 = rarely, 3 = some of the time, 4 = often, 5 = all of the time]

1. I’ve been feeling optimistic about the future
2. I’ve been feeling useful
3. I’ve been feeling relaxed
4. I’ve been feeling interested in other people
5. I’ve had energy to spare
6. I’ve been dealing with problems well
7. I’ve been thinking clearly
8. I’ve been feeling good about myself
9. I’ve been feeling close to other people
10. I’ve been feeling confident
11. I’ve been able to make up my own mind about things
12. I’ve been feeling loved
13. I’ve been interested in new things
14. I’ve been feeling cheerful

Anxiety: General Anxiety Disorder Questionnaire (GAD-7; Spitzer, Kroenke, & Williams, 2006)
Over the last 2 weeks, how often have you been bothered by any of the following problems?
[participants rate each item on a scale from 0 – 3: not at all – nearly every day]

1. Feeling nervous, anxious or on edge?
2. Not being able to stop or control worrying?
3. Worrying too much about different things?
4. Trouble relaxing?

5. Being so restless that it is hard to sit still?
6. Becoming easily annoyed or irritable?
7. Feeling afraid as if something awful might happen?

Symptoms of depression: Patient Health Questionnaire (PHQ-9; Spitzer et al., 1999)
Over the last 2 weeks, how often have you been bothered by the following problems. [participants rate each item on a 4-point scale from 0 – 3 (Not at all – Nearly every day)]

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying asleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual
9. Thoughts that you would be better off dead or of hurting yourself in some way

Sense of identity: Autism Spectrum Identity Scale (McDonald, 2017)
For each item below, please indicate how strongly you agree or disagree with that statement.
[participants rate each item on a scale from 0 – 4: Strongly disagree – strongly agree]

1. I feel like I only have autism/ am autistic/ am on the spectrum in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.
2. There is little I can do about my autism/ being autistic/ being on the spectrum.
3. I am good at some things because I have autism/ am autistic/ am on the spectrum.
4. There are some people with whom I don’t feel like I have autism/ am autistic/ am on the spectrum.
5. Autism/ being autistic/ being on the spectrum only makes things harder for me.
6. I like having autism/ being autistic/ being on the spectrum.
7. My good qualities have little to do with autism/ being autistic/ being on the spectrum.

8. I feel like I only have autism/ am autistic/ am on the spectrum around certain people, like classmates, teachers, parents, or co-workers.
9. I feel autism/ being autistic/ being on the spectrum has more benefits than challenges.
10. If I work hard enough, I can minimize my autism/ how autistic I am/ how ‘on the spectrum’ I am.
11. I would be better off if I didn’t have autism/ wasn’t autistic/ wasn’t on the spectrum.
12. I like the way I am different from everyone else.
13. I feel like I only have autism/ am autistic/ am on the spectrum in certain places, like school, home, work, or somewhere new.
14. When I’m alone, I don’t feel like I have autism/ am autistic/ am on the spectrum.
15. Autism/ being autistic/ being on the spectrum means having unique abilities.
16. If I work hard enough, I can minimize the challenges associated with autism/ being autistic/ being on the spectrum.
17. There are some people with whom I don’t feel I have autism/ am autistic/ am on the spectrum.
18. If I were “cured” of autism, I wouldn’t be me anymore.
19. I don’t feel I have additional abilities from my autism/ being autistic/ being on the spectrum.
20. I only “have autism”/ am autistic/ am on the spectrum when people treat me like I do/ am.
21. I am better off because I have autism/ am autistic/ am on the spectrum.
22. My strengths have little to do with autism/ being autistic/ being on the spectrum.

Isolation/ belongingness: General belongingness scale (Malone, Pillow, & Osman, 2012)

For each item please indicate how strongly you agree or disagree with the statement. *[participants rate each item on a scale from 0 – 6: Strongly disagree – strongly agree]*

1. When I am with other people, I feel included
2. I have close bonds with family and friends

3. I feel like an outsider
4. I feel as if people do not care about me
5. I feel accepted by others
6. Because I do not belong, I feel distant during the holiday season
7. I feel isolated from the rest of the world
8. I have a sense of belonging
9. When I am with other people, I feel like a stranger.
10. I have a place at the table with others
11. I feel connected with others
12. Friends and family do not involve me in their plans

Stigma (autism): stigma consciousness scale (Link & Phelan, 2014)
For each item please indicate how strongly you agree or disagree with the statement.
[participants rate each item on a scale from 0 – 3: Strongly disagree – strongly agree]

1. Stereotypes about autistic people have not affected me personally.
2. Most people do not judge someone on the basis of their being autistic.
3. My being autistic does not influence how people act with me.
4. I almost never think about the fact that I am autistic when I'm around others.
5. I think that people are often unfairly accused of being biased against autistic people.

Retrospective bullying: Retrospective Bullying Questionnaire
Please think back to your school days (primary and secondary). The following questions are about bullying. Bullying is intentional hurtful behaviour. It can be physical or psychological.
The following questions are about physical forms of bullying – hitting and kicking, and having things stolen from you.

1. Were you physically bullied in school?
    - Hit/ punched/ kicked: yes/ no
    - Stolen from: yes/ no
2. How often did this happen? [never/ rarely/ sometimes/ frequently/ constantly]
3. How serious do you consider these bullying attacks to be? [not at all/ only a bit/ quite serious/ extremely serious]

The following questions are about verbal forms of bullying – being called nasty names, and being threatened.

1. Were you verbally bullied at school?
    - Called names: yes/ no
    - Threatened: yes/ no
2. How often did this happen? [rarely/ sometimes/ frequently/ constantly]
3. How serious do you consider these bullying attacks to be? [not at all/ only a bit/ quite serious/ extremely serious]

The following questions are about indirect forms of bullying – having lies or nasty rumours told about you behind your back, or being deliberately excluded from social groups.

1. Were you indirectly bullied at school?
    - Had lies told about you
    - Excluded from social groups
2. How often did this happen? [rarely/ sometimes/ frequently/ constantly]
3. How serious do you consider these bullying attacks to be? [not at all/ only a bit/ quite serious/ extremely serious]

Autistic traits: Ritvo autism and Asperger Diagnostic Scale (RAADS-14)

Please respond with the answer that most accurately describes how each of the statements below applies to you. For the purposes of this questionnaire, "When I was young" refers to the age of 17 or younger.

[participants specify for each item whether it is 'true now & when young', 'true only now', 'true only when I was young' or 'never true']

1. It's difficult for me to understand how other people are feeling when we are talking.

2. Some ordinary textures that do not bother others feel very offensive when they touch my skin.

3. It is very difficult for me to work and function in groups.

4. It is difficult to figure out what other people expect of me.

5. I often don't know how to act in social situations

6. I can chat and make small talk with people.

7. When I feel overwhelmed by my senses, I have to isolate myself to shut them down.

8. How to make friends and socialize is a mystery to me.

9. When talking to someone, I have a hard time telling when it is my turn to talk or to listen.
10. Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly).
11. It can be very hard to read someone’s face, hand and body movements when they are talking.
12. I focus on details rather than the overall idea.
13. I take things too literally, so I often miss what people are trying to say.
14. I get extremely upset when they way I like to do things is suddenly changed.

Appendix P. Thematic analysis description from Phase 2

3.3.1.1 Theme 1: Wide variety of mental health difficulties. Participants described the wide variety of types of mental health difficulties they experienced, including specific diagnoses of mental health conditions, particular symptoms they have experienced and features of mental health that are distinctly autistic experiences.

Subtheme: Types of mental health difficulties. Participants reported experiencing a wide range of mental health conditions, including anxiety disorders, depressive disorders, Emotionally Unstable Personality Disorder (EUPD) and Obsessive Compulsive Disorder (OCD). They also described symptoms associated with mental health conditions, without identifying with a particular diagnosis, such as self-harm, suicidal ideation, disordered eating and symptoms of psychosis.

> *"I had become so fearful that I had quasi-psychotic symptoms – both auditory and visual hallucinations, sometimes delusions about being watched or followed. This was all just a result of intense and unresolved anxiety"* (Ptp. 18, age 25, trans male)
>
> *"So a lot of 16 I developed severe anxiety and social anxiety and then, when I was 21 I was diagnosed with depression as well one kind of wanted a bleeding into the other and I've been dealing with both since."* (Ptp. 12, age 23, male)

Subtheme: Autism-centric mental health features. Some features of their mental health difficulties were more specific or common to autistic people. Some participants described experiences of 'meltdown' and 'shutdown' when things in life were becoming difficult or overwhelming. Participants often discussed how they initially believed they were experiencing typical mental health symptoms, such as panic attacks, but following their autism diagnosis they were able to determine that they were experiencing these phenomena that are common among autistic people.

> *"Now, I didn't know at the time, so everyone was like get up and go but now because I found out about the autism it's like no stop, go to go play computer, do what you gotta do, relax and it's making a huge difference as well because, like, I would have [had] like I'm not really calling it a panic attack I'm calling it basically a meltdown…"* (Ptp. 2, age 36, cisgender male)
>
> "I can't do this and I completely just shut, what I recognize now was I shut down. I stopped talking, I stopped being able to do anything for a couple of days and I'm not sure if it was a burnout or a shutdown but it felt like it lasted a couple of days, where she just had to take me out of school." (Ptp. 16, age 31, cisgender female)

Participants also described autistic burnout, whereby they experienced extended periods of exhaustion and loss of functioning.

> *"um so I made that decision and then promptly basically slept for a week. I was so tired, I just slept, ate, toilet, back to bed. It was a situation where I got up and had food and within a couple of hours I'd have to go back to bed, because I was so tired, I was falling asleep sitting up. I'd been pushing myself that hard for so long and I hadn't even known at the time how much I was pushing myself, because the stress and, like the adrenaline I guess or something, was just keeping me. But once it was safe to relax, I was exhausted."* (Ptp. 10, age 27, cisgender female)

Experiences of 'alexithymia' were also mentioned, which is a difficulty experiencing and expressing emotions. This caused difficulties for some participants, because others could not understand why they struggled with their expressing their emotions.

> *"they asked me how I felt and I'd be like I don't know and I kept being told, because they knew my results from school and stuff, like I've been told 'you're a smart girl, I know you know how you feel', and I was like 'I don't!'."* (Ptp. 7, age 21, cisgender female)

Subtheme: Active self-management of mental health difficulties. Participants described a variety of ways in which they coped with their mental health difficulties. These included practical approaches, such as exercise, spending time alone as needed or volunteering.

> *"Then another few years of just kind of doing my thing I started volunteering with the DSPCA, I started fostering for them and just finding ways to occupy myself and look after myself and trying to build up my mental health, which was still not in a good place."* (Ptp. 10, age 27, female)

Participants also discussed adaptive and maladaptive forms of emotion-focussed coping, which included developing an understanding of emotions and accepting them, as well as repressing emotions.

> *"The years of trying to repress my emotions to the point where I was nearly emotionless had come back as a massive problem."* (Ptp. 19, age 23, non-binary)

Interests and hobbies were also highlighted as helpful coping tools. This included acting, playing computer games, art and reading.

> *"I tried to read a lot and I play alot of video games and stuff like that. I try to find interests a lot because they're good distractions if I need them."* (Ptp. 8, age 19, agender)

3.3.1.2 Theme 2: Individual context & significant events. Participants described a range of individual factors that they felt impacted their mental health.

This included genetic and physical factors, their individual profile of functioning skills, contextual factors and significant or traumatic events they experienced in their lives.

Subtheme: Biological or physical factors. Some participants noted a family history of mental health difficulties and suggested that their own difficulties may be a result of a genetic predisposition.

> *"And also my maternal side has an awful lot of mental illnesses between depression, anxiety, bipolar and narcissistic personality disorder and a whole history of it down my maternal side"* (Ptp. 16, age 31, cisgender female)

Participants also reported that hormones and physical health issues could exacerbate their mental health difficulties.

> *"...physical health has a major effect on mental health, and I know that a large part of it is the fact that pain is exhausting. And that's always going to have an effect on mental health um but yeah when I'm having a high anxiety time, it definitely contributes to the pain. When I'm having pain, it contributes to depression."* (Ptp. 9, age 35, non-binary)

Subtheme: Functioning difficulties. Participants described a variety of functioning difficulties, which impact on their ability to live alone, work or complete essential daily tasks. They also explained the variability within their support needs from day to day, as well as the very significant variability in support needs between autistic people.

> *"But in things that I would be high functioning and I'm low functioning [in] others and that's something that people don't seem to realize with autism like I'm described as quite conscientious and well spoken and articulate, but I will forget to eat."* (Ptp. 5, age 19, non-binary)

They explained how functioning difficulties impact on their mental health, and visa versa.

> *"You know, so there was kind of a time pressure thing too which of course didn't help with my anxiety about the whole thing which is like, oh God how am I going to learn how to be a proper grownup like while my parents are still able to help like."* (Ptp.10, age 27, cisgender female)

Subtheme: Contextual factors & significant life events. Participants' life circumstances and contexts impacted their mental health. For example, severe financial difficulties, religious upbringing and COVID-19 restrictions. Some also reported that having family members, such as parents, siblings or children who required care impacted on their mental health, often due to a lack of other available supports.

> *"I mean, I was the one who was trying to save her. I feel like I've spent my entire life trying to save my family, you know it's like it's always been my job, for some reason I was always seen as a strong one. Yeah I still am, I still get that, even now I still get that. You know people think that I'm really tough and hard and thick skinned and I'm not at all, I never have [been] even a little bit."* (Ptp. 17, age 50, non-binary)

Participants also reported significant bereavements that impacted their mental health. One participant described how he began using alcohol to cope following the death of a close friend:

> *"That devastated me, that destroyed me, it completely destroyed me I hadn't touched a drink all my life, he died, I started drinking on the weekends."* (Ptp. 2, age 26, cisgender male)

Other significant life changes also had impacts on mental health, such as moving house, parents separating or moving schools. Participants appeared to find it particularly difficult when multiple significant changes or events happened over a short period of time, leading to very high levels of distress and even suicidality.

> *"My beautiful rabbit, Jack, passed away suddenly. Some friends moved away. Life became unbearable, so at the start of January 2019 I tried to end my life."* (Ptp. 18, age 25, trans male)

3.3.1.3 Theme 3: Social connection & support. The importance of social connection and social support was evident in participants' descriptions of their experiences. Participants described people in their lives who promoted their mental health, through providing a sense of belonging, acceptance and support. They also described challenges and barriers in relationships, which were detrimental to their social wellbeing and mental health.

Subtheme: Belonging, acceptance & support. Participants described a strong desire to be accepted among their peers and identified characteristics of friendships (or other relationships) that were positive for their mental health. They described finding friends who they fit in with naturally, often others who also did not fit in with the neurotypical majority.

> *"I had a couple of very good friends in primary school, but they were both kind of strange, like me."* (Ptp. 17, age 50, non-binary)

They also described friends who were understanding and accommodating to their needs and preferences as an autistic person.

> *"Those who've always toughed it out and sort of supported me, had the conversations about kind of my own experiences with autism, so they've made the effort to learn as well, which is, which has been really kind of helpful*

> *helping me kind of protect my mental health more than sort of the ones who not really or any fault of their own as well somewhat damaged it.”* (Ptp. 12, age 23, cisgender male)

Participants consistently spoke of the importance of having supportive people in their lives, especially when they were struggling with their mental health or needed to talk through some challenges they were facing. They described supportive friends, family members, partners, support groups, online communities and even animals.

> *“I will speak to my mother, I suppose, about it and she's been really, really great.”* (Ptp. 11, age 20, cisgender male)
>
> *“[My dog] understands me in a way no one else can and she's the only person I feel comfortable making eye contact with. She checks in on me throughout the day and nudges me to bring me back to the present when I leave my body/the environment. She is an emotional support animal and I take her with me sometimes to pick up groceries/essentials or if I need to take public transport. She gives me love and care and freedom and independence.”* (Ptp. 18, age 25, trans male)

Participants spoke of finding belonging, acceptance and support within the autistic community. They explained how it is easier to relate to other autistic people and described an immediate sense of belonging and understanding when with autistic people.

> *“I relate more to people halfway across the world than I do in my own local community. In that we have common and shared experiences we've common viewpoints and common behaviours so the same way neurotypical people feel all the time, I feel like that when I engage with people online and sometimes in real life it's-it's been fantastic.”* (Ptp. 3, age 26, cisgender male)

Subtheme: Challenges & barriers to connection & support. Unfortunately, participants often described challenges and barriers they faced in developing and maintaining such meaningful social connections (see also ‘Theme 4: Stigmatisation & victimisation of autistics’ for negative experiences with peers). Participants described difficulties identifying suitable potential friends/ partners, as well as experiences of being rejected by potential friends due to being ‘different’.

> *“It is hard to make and keep friends as the minute they see I am not like them they walk away”* (Ptp. 20, age missing, cisgender female)

They also describe insecurity in friendships once they do develop, often due previous negative experiences of friendships not lasting.

> *“I go into a lot of relationships just kind of expecting them to end before they get the chance to start because that's how they usually go I usually talk to a person for a month or two we get really close and then, for whatever reason, they just can't keep it up, we end up drifting.”* (Ptp. 8, age 19, agender)

Other barriers include having different social preferences to peers, perceived lack of experience in friendships and anxiety in social situations.

> *“But yeah for a long time, like I didn't feel comfortable going on nights out, I wasn’t able to go to your house party and even then it was only people like I was really, really good friends with like I wouldn't just go to sort of someone a casual acquaintance.”* (Ptp. 12, age 23, cisgender male)

Participants also described the devastating impact when a friendship or relationship did not work out, as well as the impact that a lack of meaningful social connection had on their self-esteem and mental health.

> *“Oh yeah massively yeah, like it's you know, we all like, we're communal creatures like so we all like, want to be accepted, and not been in a*

> *partnership or relationship like it basically singles you out to think that there's something wrong with you*" (Ptp. 2, age 36, cisgender male)

3.3.1.4 Theme 4: Autistic identity & self-perception. Participants discussed their individual experiences of coming to the realisation that they are autistic (which may or may not include a formal diagnosis), developing an understanding of what it means for them to be autistic and the process of embracing their own autistic identity.

Subtheme: Realising one's autistic identity. The experience of realising they are autistic was often discussed by participants, especially those who did so in adulthood. For some this occurred when they received a diagnosis, while for others this occurred through a process of self-identification. Regardless, the impact of the realisation was overwhelmingly positive for participants; they described their reactions of joy, relief and liberation.

> *"And that was where the liberation came in and the great feeling of relief and the whole kind of like no, taking the yoke off your back and just being able to breathe"* (Ptp. 16, age 31, cisgender female)

Unfortunately, for many there were significant barriers involved in this process. This included service-related barriers to a formal diagnosis, such as the unavailability of an adult assessment service in Ireland. While private assessments were available, these were financially prohibitive for some.

> *"My GP said kind of good luck with that, you're at the age you are, you're in your late 60s, you know it's very expensive, it's very rare, you're on a medical card, you know."* (Ptp. 15, age 72, cisgender female)

There were also societal barriers, such as out-dated and inaccurate views of what autism is, leading to participants' traits not being highlighted and assessed in a timely way. These issues seemed to disproportionately impact female participants and trans participants who were assigned female at birth. One participant described how their mother did not take them seriously when they suggested they may be autistic:

> *"Her understanding of autism was just a wise skinny teenage boy that couldn't make eye contact and always did a flapping hands [...] stimming."* (Ptp. 5, age 19, non-binary)

Another described a medical professional who did not believe she could be autistic:

> *"And then, when I said to doctors that I wanted an assessment, they said but you're not autistic. And I said why? And they said well, you're in here talking to me, this is not an autistic thing, and I said no, and they said, well, you have feelings that's not an autistic thing."* (Ptp. 16, age 31, cisgender female)

These barriers to an autism diagnosis resulted in participants spending many years struggling due to a lack of self-understanding and support, as well as unrealistic expectations being placed on them.

> *"You know. So it was from a young age, I was trying to be perfect, And as you get older, the cracks start to show. Especially when you don't understand why you're having so much trouble with these things. You know I didn't have an excuse, it was just. You know, she just must not be trying hard enough."* (Ptp. 10, age 27, cisgender female)

Participants also reported being mis-diagnosed with other conditions, such Bipolar Affective Disorder and EUPD, before eventually being diagnosed (or self-identifying) as autistic. For one participant this led to inappropriate and damaging treatments:

> *"I mean somebody suggested, I might have bipolar and so I was prescribed lithium by a doctor in [city in UK] and it made not the slightest bit of difference, it did actually damage my hearing, unfortunately. They monitored*

> *the lithium but unfortunately it damaged my hearing and gave me tinnitus, which I have to this day."* (Ptp. 15, age 72, cisgender female)

On the other hand, some facilitators of receiving a diagnosis were also described. The availability of accurate information about autism was crucial in facilitating diagnosis or self-identification, as participants often learned about autism from friends, family members and mental health professionals, or through books or online resources, which set them on a path to discovering their autistic identity.

> *"I think he said it to me when I was a teenager, and so this was massively helpful, because I would have never figured it out otherwise and the fact that he was willing to just say to me look [Participant 3] I think you're autistic. He used the term Asperger's, I don't like that term. If he hadn't said that to me I wouldn't have gone on the journey that led me to my… my happiness over the past three years"* (Ptp. 3, age 26, cisgender male)

Subtheme: Understanding & embracing one's autistic identity. Many participants (primarily those who were diagnosed in adulthood) spoke of a process of self-understanding that came with receiving a diagnosis or self-identifying. They described how they were able to make sense of past experiences:

> *"It made sense like everything, everything up until that point and then everything like, I don't know, it just explained a lot of things that didn't make sense before. The other diagnosis, yes, it made sense but they didn't cover everything and this even explained those."* (Ptp. 7, age 21, cisgender female)

They also described how they began to honour their own preferences, validate the challenges they faced and better manage their mental health difficulties as a result.

> *"It was just a massive relief to me because, when you do have mental health issues, there is a kind of shame, Especially in this culture as well, like so I felt*

> *kind of ashamed about it, and I felt that, like I had done it I let it get this bad, but when I got diagnosed it was kind of like well you didn't have all the information, And because he didn't have all the information you couldn't fix what you needed to fix or change what you needed to change or adapt.”* (Ptp. 2, age 36, cisgender male)

Overall, this enhanced self-understanding appeared to lead to a more positive autistic identity, whereby participants took pride in being autistic and recognised the strengths associated with being autistic. In addition, those diagnosed in adulthood felt that an earlier diagnosis would have saved them from a lot of self-criticism and distress.

> *“If I would have received a diagnosis during my teenage years, I wouldn’t have been so hard on myself and forgive myself for my behaviour which I could not control. I have developed a need for high achievement to make myself feel worthy and better. “Nearly like a child saying look what I can do, would you love and accept me now?’”* (Ptp. 20, age missing, cisgender female)

On the other hand, some participants spoke of the impact of others’ negative perceptions of autism on their own sense of identity and self-esteem. These participants were mostly those who were diagnosed in childhood and experienced the negative views of parent, teachers and professionals.

> *“...knowing that half your family don't even accept you for who you are is not easy and like it wasn't something he made a point of a lot but it's just something he brushed under the carpet like if I said anything about being autistic he would change the subject [...]as I started finding out more about autism and started accepting it myself, I was a bit mad about it but, at the time it felt right because I was in a negative mind-set about autism, and it makes*

> *sense in hindsight, given how the people around me were behaving about it."* (Ptp. 14, age 24, cisgender female)

Regardless of the timing of their diagnosis, many participants described self-criticism and self-blame, which was linked to their mental health. This often seemed to be linked to internalised stigma about being autistic, for example in relation to stimming or difficulties in friendships.

> *"It made me… I was always a bit critical of myself and don't get me wrong, I was never a perfect friend, I did say things that upset them too, heavily upset them at times, which I would love to take back at any opportunity I could, but I can't. But it didn't do a lot for my self-*esteem*. It was kind of the final nail in the coffin. That head me [sic] towards depression"* (Ptp. 12, age 23, cisgender male)

3.3.1.5 Theme 5: Stigmatisation & victimisation. Participants described others' negative attitudes and harmful behaviours towards them and the impact of these on their mental health. The way they were treated was generally put down to them being autistic, which had an effect on how they viewed themselves and their autistic identity (see theme 4: Autistic identity and self-perception).

> *"…like your teachers turning the other cheek to people, just like right in front of them and broad daylight, excluding you and doing hurtful things. And the fact that people in authority let that happen and went along with that, like even these people who are older than me, and you know, are more powerful than me, even they kind of agree with the bullies stance. It doesn't do a lot for your self worth. It kind of just reinforces what you're already thinking about yourself."* (Ptp. 14, age 24, cisgender female)

Subtheme: The lasting impact of childhood bullying. A large majority of participants discussed being bullied as a child and often referred to this as being the initial trigger for mental health difficulties.

> *"Oh, I was constantly bullied, like continuously bullied, like all through like primary school and secondary school like, no matter what I did, I just couldn't, I just couldn't not get bullied like I tried everything I tried to fit in, I tried doing everything it just didn't happen"* (Ptp. 2, age 36, cisgender male)

Some participant reported being bullied explicitly for being autistic, while others alluded to aspects of their autistic characteristics being targeted by bullies, such as having different interests, being hyperlexic or having food sensitivities.

> *"I was a weird kid and it's one of those things of like people say that they don't make fun of autism but oh boy do they make fun of autistic behaviour."* (Ptp. 9, age 35, non-binary)

Participants described that it was particularly hurtful or distressing when adults, such as teachers, would allow the bullying to happen, or even join in.

> *"And you know that makes it.. it wasn't just the children, it was the teachers as well, I had one teacher in primary school that was particularly, he just hated me. I would have done anything. I would have stood on my head for an hour if it would make him stop hating me and stop treating me the way that he did."* (Ptp. 17, age 50, non-binary)

As well as explicit bullying, participants also experienced social exclusion and rejection by peers. Being seen as different meant they were always on the outskirts of the social group, or excluded and isolated entirely.

> *"I suppose it wasn't something I had much of a concept of until Maybe my teens and I suppose that's because things got really hard for me at school. I,*

> *like a lot of autistic people, I had a lot of issues with isolation and not being accepted by my peers in school and I supposed that accelerated in secondary and I tie a lot of the issues I struggle with still to this day back to that time in my life when I didn't really feel like I had much support. I was in a community that was quite hostile to me being there."* (Ptp. 14, age 24, cisgender female)

Subtheme: Abuse & victimisation. Aside from childhood bullying, other forms of victimisation described by participants as factors that contributed to mental heath difficulties. Participants mentioned experiencing family-related trauma, sexual or gender-based violence and physical abuse.

> *"Now, obviously, due to my past traumas, the molestation, rape and then the attack from my father, it all kind of made me very, very weary of men, I'm still very weary of men at this stage so when I shared a house with another man, I was terrified, so that definitely added to negative impacts."* (Ptp. 16. age 31, cisgender female)

Participants also reported feeling more vulnerable to abuse due to being autistic, perhaps due to not picking up on social signals that indicate someone may have ill intent.

> *"It is, I know that in general I'm an easy target for a lot of things like with friendships. I wind up in toxic friendships so often because I'm not good at recognizing what normal is. Because I've never really had normal."* (Ptp. 9, age 35, non-binary)

Some participants also reported more subtle forms of abuse, such as the invalidation of their experiences, causing them to sit through experiences that cause them pain.

> *"...it would be like a metal pin being gradually shoved into my head and a headache would spread back, and it would hurt all over my temples and you*

> *know I would have to close my eyes and then the teacher would go, you know, give me grief for falling asleep in class, and I would try to say I'm not falling asleep, my head really hurts, and they would think that was you know, just looking for attention just making excuses. So I learned to force myself to ignore the pain with so many things."* (Ptp. 17, age 50, non-binary)

Subtheme: Stigma & ableism. Participants discussed experiences of stigma, ableism and resulting discrimination. They felt that being autistic limited the opportunities they had available to them, due to others' perceptions of autistic people.

> *"Because like there's a lot of infantilization now of [autistic people] [...] there are some times, where like, we need to be told what to do on things. But for the most part we're capable of making decisions and we're capable of understanding things, so if you explain it to us, and if you treat us with respect it's going to go a long way."* (Ptp. 9, age 35, non-binary)

They also discussed the impact of ableist and deficit-focussed narratives of autism on their own self-esteem and mental health. They experienced ableist comments in a range of situations, including in the workplace, from healthcare professionals and while dating.

> "I went on a date with a girl a few years ago and this was around the time I was figuring out I was autistic and I mentioned it to her and she said 'you can control it, right?' as if, you know, something is wrong with me. That was just one example of explicit ableism." (Ptp. 3, age 26, cisgender male)

Fighting against this abelism and stigma by educating others about autism was commonly mentioned by participants. They described feeling a sense of responsibility to advocate for themselves and their autistic peers. They also gained satisfaction and felt empowered by sharing their experiences and described very supportive responses from others, which was positive for their mental health.

> *"And for autism awareness month I kind of did a bit of a fundraiser for AsIAm, but my dad got very involved as well and started reading a lot of things, and some of my friends did as well, so that was really good, that was really kind of really boosting*" (Ptp. 12, age 23, cisgender male)

3.3.1.6 Theme 6: Navigating the neurotypical world. Many participants spoke of the challenges that arose while interacting with the neurotypical world that was often incompatible with their needs or preferences. As a result, participants often described a build up of small day-to-day stressors that become too overwhelming to manage.

> *"…everything was really difficult, I found it difficult to do just normal everyday interactions. Things that I have to do, that other people seem to be able to manage better than me, and the anxiety of that would build up and build up, and it would just become too much."* (Ptp. 4, age 42, cisgender female)

Subtheme: Sensory experiences. Participants regularly described how particular sensory environments or stimuli would cause sensory stress or sensory overload, which could subsequently lead to panic attacks, meltdowns or shutdowns.

> *"By in fifth and sixth year I started having a lot more sensory overload in class and I started to get really scared and nervous that I was gonna have a meltdown there in front of everybody."* (Ptp. 5, age 19, non-binary)

Such sensory stress also creates a barrier to fully engaging in many different settings, such as academic, work and social scenarios, impacting on quality of life.

> *"I suppose anywhere that's it's crowded, if it's noisy, and if you can't hear the conversations , those are the places that are really difficult… and I suppose very on edge and I usually just bolt out of them I don't tend to stay very long in those situations"* (Ptp. 4, age 42, cisgender female)

Subtheme: Predictability vs. ambiguity. Participants discussed how predictability, routine and structure were helpful for their mental health. They described depending on routine to maintain the habits that kept them feeling mentally well, as well as predictable situations and outcomes having a grounding impact.

> *"I do better when there's a routine like mentally because I do better when I have expectations that I have to do. In terms of like at 10 you'll be here, 11 you'll do this, stuff like that."* (Ptp. 8, age 19, agender)

On the other hand, novel situations, unpredictability and uncertainty, which are commonplace in a neurotypical environment, was reported to cause stress and anxiety.

> *"I'm very happy at work. I've been there for 20 years now, so I know the people and they know me. But anything different that's out of the routine, well, that brings back a spike in stress levels."* (Ptp. 4, age 42, cisgender female)

Subtheme: Autistic skills and common attributes. Participants spoke about how their needs and preferences were often not met in educational and work environments. Often, accommodations that were needed were not provided by employers or educational institutions. This inflexibility of the systems caused stress and burnout for many participants.

> *"And that's not a healthy or sustainable way to do this, it makes a lot more sense to do this part time and not burn out or burn out far less frequently and actually get somewhere and they were like sorry that's the one thing we can't*

> *give you. So I was like okay well that's that then. I was just like okay schools not happening."* (Ptp. 10, age 27, cisgender female)

They regularly found themselves in work or educational contexts that were not suited to their skills, though some excelled when their job or area of study was aligned with area of interest or skill set. One participant expressed her frustration around the under-used and under-appreciated skills of autistic people:

> *"I speak several languages, I have a lot of skills, I can build things out of wood, I know a lot about animals. I mean you know… There's all these skills. There's all these highly skilled autistic people by our very nature, we don't do things by halves, you know when we get interested in something we get completely obsessed with it learn everything there is to know about this huge skill pool going to waste."* (Ptp. 17, age 50, non-binary)

Participants also described some psychological attributes that were common among autistic people but not well suited to a neurotypical world. These included honesty, increased sensitivity and perfectionism.

> *"At the end of the day, it's an important thing to have in mind that sometimes we're sensitive to the world in a different way and that's not a bad thing or a good thing, but it's something that people need to understand, in order to truly have like equitable the world in terms of like how we distribute our mental health services and everything."* (Ptp. 14, age 24, cisgender female)

Subtheme: The weight of neurotypical social expectations. Challenges associated with keeping up with neurotypical social standards and expectations were often discussed among participants. Participants reported feeling confused by the neurotypical world and feeling pressure to fit into it, without knowing how.

> *"My autism also makes it difficult to acclimatise to daily life where I'm expected to conform to neurotypical expectations and it can be hard sometimes trying to deal with that."* (Ptp. 8, age 35, non-binary)

This included adapting to neurotypical communication styles and preference, which was often incompatible with autistic styles of communication, leading to confusion and miscommunication. Autistic communication styles were perceived as rude and tended to be considered inferior to neurotypical communication. This mis-match could cause difficulties in relationships or in the workplace.

> *"I didn't realize at the time I was being judged by an unfair standard like I'd be judged by neurotypical communication standards. So that was that was hard for me to deal with, so I was expected to be more polite and suffer that, instead of just getting the point across which is all communication is."* (Ptp. 3, age 26, cisgender male)

These expectations, and the risks associated with not meeting these expectations (see theme 4: stigmatisation and victimisation of autistics) led participants to engage in masking in an effort to be accepted and thus not ostracised or victimised by their peers.

> *"I like I put down to mimicking others like, literally because it seemed like the thing to do, because, like I just didn't want to be bullied so what I did was I learned I watched the people who weren't getting bullied and tried to mimic them and their personalities."* (Ptp. 2, age 25, cisgender male)

Participants also discussed the impact of this masking on their mental health, describing anxiety, exhaustion and burnout.

> *"So that's about nine but yeah realizing when I was in fifth class that I was not normal and then really quickly trying to catch up with everybody and start*

kind of, I obviously started masking very young and trying to act like the other people and not having a clue what was going on, it pushed my anxiety like through the roof" (Ptp. 16, age 31, cisgender female).