"Don't treat autistic people like they're a problem, because we're not!": An exploration of what underpins the relationship between masking and mental health for autistic teenagers

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Thesis declaration form

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

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Overview

Autistic people have described masking, or 'camouflaging', parts of the self in order to avoid repeated bullying, discrimination, social rejection and in order to meet neuro-normative social expectations. This thesis explores the relationship between autistic people's experiences of masking and mental health. This thesis is one of multiple UCL doctoral projects investigating masking in autistic teenagers.

Part 1 is a conceptual introduction to autism, mental health and masking. Explanations for the increased prevalence of mental health difficulties for autistic people are explored. Masking is identified as a potential factor mediating this relationship. The review discusses different ways of conceptualising masking and explores the drivers and consequences of masking for autistic people. The review concludes with a summary of existing research into the relationship between masking and mental health difficulties.

Part 2 is a qualitative study seeking to understand autistic teenager's experiences of masking and how this relates to their mental health. Semi structured interviews were conducted with 20 autistic teenagers and transcripts were analysed using thematic analysis. Bidirectional relationships between masking and negative mental health related factors, and conversely between authenticity and positive mental health related factors, were described. Both processes were driven by social and environmental factors. The findings support a broader conceptualisation of masking and have implications for diagnostic and therapeutic clinical services.

Part 3 is a critical appraisal of the research process. Personal reflexivity is used to consider the impact of the researcher's perspective on the research. Introspection is used to identify broader theoretical perspectives to inform system-

level implications of the research. Reflections on the essentiality of co-production are also presented.

Impact Statement

Academically, this study broadens the existing conceptualisation of autistic masking. It adds detailed qualitative descriptions from autistic teenagers about their experiences of masking. The sample includes 10 autistic teenagers who identified as male and 10 who identified as female which is particularly useful as previous research into masking has often focused on autistic girls.

Previous research has identified that autistic teenagers are more likely to experience mental health difficulties and that there is a statistical association between masking and mental health. The current study identifies some of the factors and processes involved in these relationships.

The current study also provides suggestions for improvements to academic teaching about autism, in order to change social narratives about autistic people.

Outside of academia the current research has several clinical implications. As an understanding of masking develops, clinicians in autism diagnostic services can improve their identification of autistic young people who do not meet inadequate criteria or outdated clinical profiles. Diagnostic tools can also be improved according to a more detailed understanding of masking.

The results of this study can also help to inform post-diagnostic support and information offered to families. It emphasises the importance of the information giving being non-pathologising and aiming to foster a positive autistic identity and support to identify environments likely to facilitate authentic expression and interactions. Additionally, this study has important implications for therapeutic interventions for autistic young people experiencing mental health difficulties. Therapists must have a good understanding of masking, the social environmental

drivers of both masking and mental health difficulties and the mental health consequences of masking. Masking, social and environmental factors, and societal messages about autism should be built into psychological formulations.

A further impact of this study is highlighting the potential long-term negative consequences of social skills groups for autistic young people. The study should be used to encourage identity positive group interventions, which are co-produced and facilitated by autistic adults.

Finally, this study highlights a need for system-level changes across clinical, research and educational settings in order to move away from the damaging deficit-based narratives of autism currently embedded.

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Part I: Conceptual Introduction

What is the relationship between masking and mental health for autistic people?

Abstract

Autistic people have an increased chance of experiencing mental health difficulties across the life span. One explanation for this highlights the social and environmental context to autistic people's experience of the world, which includes increased experiences of bullying, exclusion, and discrimination. This hypothesis can be further informed by recent research into masking. Masking involves the suppression of one's authentic, autistic self and 'putting on an act' to appear neurotypical (Hull et al., 2017). Reasons for masking include to stay safe (i.e. avoiding bullying, violence or discrimination), experiencing shame relating to being different, to assimilate to neuro-normative expectations, and to obtain social acceptance and connection. A range of mental health consequences to masking have been identified in the literature including stress, anxiety, exhaustion, depression, loss of identity, social isolation, disconnection and suicidality. Social oppression and exclusion, burnout, a lack of support and minority stress have been identified as possible drivers of the relationship between masking and mental health. Further research is needed, particularly with autistic young people, to better understand the directionality, underpinnings and development of the relationship between masking and mental health.

Introduction

Research into mental health interventions that are appropriate and effective for autistic people has been identified as the number one research priority by the autistic community (Warner, Cooper, & Cusack, 2019). Autistic people are more likely to experience mental health problems than non-autistic people, and multiple factors appear to contribute to this. Social context plays a key role; autistic people experience high rates of bullying, exclusion, trauma and discrimination. Autistic people have described navigating this social context through the conscious and unconscious process of 'masking'. Driven by a desire to stay safe, to assimilate in response to societal pressure, and to find acceptance in educational and occupational settings, masking involves suppression of the autistic self and the presentation of the self as non-autistic. Research has identified a statistical relationship between masking and mental health problems in autistic adults. How masking may develop in autistic young people is not yet understood. Equally, more research is needed into the underpinnings of the relationship between masking and mental health, particularly in autistic adolescents. This conceptual review will consider existing theory and research into mental health, masking, and the relationship between the two in autistic people.

What is autism?

There is currently debate about how autism should be defined, focusing on whether it should be considered a disorder, or a form of difference. Current diagnostic manuals (American Psychiatric Association, 2013) define autism as a developmental disorder characterised by deficits in social communication, interaction and restricted and repetitive behaviour. A deficit-based understanding of autism has

been widely critiqued by autistic self-advocates, as well as groups of clinicians and researchers (for example; Milton, 2012; Harvey, 2018; Rose, 2018). There is evidence from genetic, neural, behavioural and cognitive research that 'difference' is a more accurate description of autism than 'deficit'. Genetic, neural, behavioural and cognitive research findings show that autism can be most accurately understood as 'difference', that autistic people experience disability, but there is minimal evidence that autism should be understood as a 'deficit' (Baron-Cohen, 2017). The neurodiversity movement argues for the recognition of autism as an example of neurodivergence. Neurodiversity refers to the wide variation in neurocognitive functioning within our species, none of which is 'normal', and all of which are simply different (Silberman, 2015). Many have advocated for discarding deficit-based, medicalised conceptualisations of autism, regarding them as both inaccurate and stigmatising, and instead developing an appreciation for autism as a genetically-based human neurological variant, characterised by differences in sensory processing, information processing, social cognition, interests, and social interaction style (Sutton, 2015; Silberman, 2015).

Throughout this paper, identity-first language will be used (i.e. 'an autistic person'), rather than person first language (i.e. a 'person with autism'), to reflect the best data available on the terms most endorsed by autistic people (Kenny et al., 2016). Identity-first language may serve to challenge a more medical conceptualisation of autism and instead foster more positive autistic identities, highlighting strengths and differences within a neurodiversity framework. However, it is also acknowledged that the existing research into the language preferences of people on the autism spectrum is not without its limitations, and there is a great deal of variability in preferences regarding language (Shakes & Cashin, 2019).

Autism and Learning Disabilities

It is estimated that half of autistic people also have a learning disability (Fombonne et al., 2011; Emerson & Baines., 2010). Over 95% of autistic children also experience at least one co-occurring developmental, mental health, or physical health condition or symptom (Soke, Maenner, Christensen, Kurzius-Spencer, & Schieve, 2018). The experiences and support needs of autistic people vary widely depending on these co-occurring conditions, an individual's idiosyncratic experience of being autistic, and a range of environmental and contextual factors.

Labels such as 'high functioning' and 'low functioning' are not medical terms, but are sometimes used in clinical and research settings in an attempt to give more information about an autistic person's abilities and difficulties. 'High functioning' tends to be used to describe members of the autistic community who do not have any learning difficulties and who have higher verbal abilities. However, these labels perpetuate unhelpful assumptions, for instance that people who do not communicate verbally or have a learning disability do not have abilities or a voice, or that autistic people who do not have a learning disability, or who do communicate verbally, do not have important support needs (Thomas, & Boellstorff, 2017). Additionally, cognitive abilities are a poor predictor of functional abilities, particularly for autistic people who do not have a learning disability (Alvares et al., 2020). Thomas and Boelstorff's ethnographic research with autistic communities explores the impact of 'the spectrum' metaphor. They consider alternative frameworks, which move away from a spectrum where 'some autistics are 'worse' than others', and instead take a de-medicalised and de-stigmatising approach to capturing an autistic individuals' specific support needs, strengths, difficulties and abilities.

Masking research to date has focused on the experiences of autistic people who predominantly communicate verbally, do not have learning disabilities, but many of whom are likely to be experiencing a range of other mental health difficulties, physical health difficulties and other neurological differences.

How likely are autistic people to experience mental health difficulties?

A high proportion of autistic children and adolescents experience mental health difficulties. Anxiety difficulties are experienced by most 1-17 years old on the autism spectrum and depression is experienced by about half of these children and adolescents (Mayes, Calhoun, Murray, & Zahid, 2011). Simonoff et al. (2008) found that 70% of a community sample of 112 autistic 10 to 14-year olds, were experiencing at least one mental health difficulty, and 41% were experiencing two or more. This is a particularly striking finding as the recruitment of a community sample avoids the limitation of a clinical sample where estimates of co-occurring conditions are often inflated.

Autistic adolescents (11 to 17-year-olds) report significantly more symptoms of mental health difficulties than non-autistic adolescents (Hurtig et al., 2009), as measured by the Youth Self Report (Achenbach & Rescorla, 2001). Autistic adolescents were more likely than neurotypical peers to report feeling withdrawn from others, anxious, low in mood, and to have attentional difficulties. Higher rates of depression have a huge impact on the daily lives of autistic young people (Mazzone et al., 2013), including for life at home, at school, and socially. Autistic children also experience suicidal ideation and attempt suicide more frequently than non-autistic children. Fourteen percent of 791 autistic children (aged 1-16 years old) were rated by their mothers as 'sometimes' to 'very often' experiencing suicidal

ideation or attempts (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013). This was 28 times more often than for non-autistic young people.

These high rates of co-occurring mental health problems of autistic people are not limited to childhood and adolescence. Rather, they persist across the lifespan. Lever and Geurts (2016) found that 79% of 247 autistic adults had experienced a mental health difficulty at least once across the lifespan. The finding continues into later adulthood; Hand and colleagues' (2020) cohort study found autistic older adults also experienced high rates of mental health difficulties than their non-autistic peers. Notably, autistic older adults were 11 times more likely than non-autistic older adults to have a healthcare encounter for suicidality or intentional self-injury.

Pooled estimates of the different mental health difficulties experienced by autistic people vary greatly. Lai et al.'s (2019) meta- analysis investigated this using current diagnostic labels and estimated that 10-27% autistic people were diagnosed with an anxiety disorder, 7-20% had a depression diagnosis, 8-13% were diagnosed with OCD, 8-13% with conduct disorder and 3-7% with bipolar disorder. Considering the significant barriers to autistic people receiving appropriate mental health assessment and support (Crane, Adams, Harper, Welch, & Pellicano, 2019; Cassidy, Bradley, & Bowen, 2018b), we can assume the true prevalence rates are higher than stated here.

Mental health experiences within the autistic community are, of course, extremely variable. Age, gender, intellectual ability and country of study all contribute to high levels of variance in estimates of the prevalence rates of mental health difficulties experienced by autistic people (Lai et al., 2019). For instance, Lai's study found that depression, bipolar and schizophrenia are more prevalent diagnoses as age increases, and depression appears to be a diagnosis given more

commonly to autistic women than to autistic men. These patterns were noted to mirror those found previously in non-autistic populations.

Why are autistic people more likely to experience mental health difficulties?

Autistic people of all ages have an elevated chance of experiencing mental health difficulties, however the reasons for this are not well understood (Rosen, Mazefsky, Vasa & Lerner, 2018). Various explanations have been proposed and can be summarised into four broad, yet non-mutually exclusive, hypotheses.

Hypothesis one: Autistic traits overlap with symptoms of mental health difficulties

Firstly, it has been proposed that prevalence estimates of mental health difficulties in autistic people may be inflated, due to an overlap between autistic traits and the symptoms of some mental health problems. For instance, autistic traits have been noted to partially overlap with symptoms of social anxiety and obsessive-compulsive disorder (Cath, Ran, Smit, Van Balkom, & Comijs, 2008), and it could be that autistic traits are being mis-identified as symptoms of mental health difficulties. A key criticism of this explanation is the superficial similarities between autism and various mental health difficulties and evidence has emerged emphasising distinct phenomenology (for example; Kleberg, Högström, Nord, Bölte, Serlachius, & Falck-Ytter, 2017).

Hypothesis two: Autism and mental health difficulties share neural and genetic underpinnings

A second explanation emphasises some of the shared genetic and neurological factors which may underly both autism and various mental health difficulties. For instance, Hallett et al., (2013) found that autistic children and their

non-autistic co-twins, both those with and those without characteristics of the broader autism phenotype, showed heightened generalised and social anxiety. This indicates a familial association between autism and anxiety. Particular neuro-cognitive processes, such as executive function difficulties, may also be involved in both autism and anxiety (Hollocks, Jones, Pickles, Baird, Happé, Charman, & Simonoff, 2014). There is also an overlap in some of the genes relating to the likelihood of being autistic and of experiencing various mental health difficulties (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013). Despite this, autistic traits and anxiety have also been found to relate to distinct neural correlates of certain cognitive processes, such as reward processing (Mikita et al., 2016). There is much that is currently still currently unknown about the shared and distinct neural and genetic underpinnings of autism and anxiety (Rylaarsdam, & Guemez Gamboa, 2019).

Hypothesis three: Autism is a direct risk factor for developing mental health difficulties

A third possibility is that being autistic is a direct risk factor for developing mental health difficulties. A cohort study of children and adults found that 'autistic like traits' increased the risk of experiencing mental health problems including anxiety, depression, and substance misuse. It is possible that specific autistic traits directly increase the risk of experiencing mental health difficulties. For instance, in autistic children, higher levels of sensory hypersensitivity is associated with increased internalising problems such as anxiety, depression and phobias, and increased externalising problems such as communicating through aggressive behaviour (Tseng, Fu, Cermak, Lu, & Shieh, 2011; MacLennan, Roach, & Tavassoli, 2020). Alexithymia, a difficulty identifying and describing feelings which is

common in autistic people (Hill, Berthoz, & Frith, 2004), is also associated with increased anxiety in autistic adolescents (Milosavlijevic et al., 2016). Additionally, children who score higher on measures of social communication difficulties aged seven are more likely, in adolescence, to experience depression (Rai et al., 2018) and are at a higher risk of suicidal thoughts and self-harm with suicidal intent (Culpin et al., 2018). It may be that these social, sensory, emotional processing differences directly increase the psychological and emotional stress experienced by autistic individuals in their daily lives and increase the likelihood of experiencing mental health difficulties.

Hypothesis four: Mental health difficulties are mediated by the social and environmental context

A final hypothesis proposes that autistic traits do not directly increase the chance of an individual developing mental health difficulties. Rather, being autistic or having autistic traits occurs within a social and cultural context, and experiences within these contexts increase the likelihood of autistic people developing mental health difficulties. The social model of disability describes how factors external to the individual often cause disability or disabling experiences (Shakespeare, 2006). For instance, differences in social communication are unlikely to cause distress if they are not punished by our social peers. Indeed, after Rai et al., (2018) assessed for mediating factors, they found that there was no evidence of an association between social communication difficulties and depression, after controlling for experiences of bullying.

Autistic adults are more likely to have experienced various negative life events, including unemployment, financial difficulties, victimisation and bullying, and these experiences contribute to the increased chance of developing mental health

difficulties (Griffiths, Allison, Kenny, Holt, Smith, & Baron-Cohen, 2019). Emerging evidence suggests that autistic children and young people are more likely to have experienced stressful and traumatic life events than their non-autistic peers (Berg, Shiu, Acharya, Stolbach, & Msall, 2016; Taylor and Gotham, 2016), and the experience of trauma increases the risk of developing mental health problems (Fuld, 2018).

Non-autistic people's attitudes and behaviour towards autistic people impacts upon autistic people's mental health. For example, Cage, Di Monaco, & Newell (2018) examined the experiences of autism acceptance amongst 111 autistic adults. Only 7% of participants said 'yes' when asked whether they feel society, in general, accepted them as an autistic person, 43% said no and 48% said sometimes. This is perhaps unsurprising in relation to other findings that, for instance, adults who work with children hold more negative implicit attitudes towards autistic children compared to their non-autistic peers (Kelly & Barnes- Holmes, 2013). Additionally, non-autistic people judge autistic people less favourably after viewing just ten seconds of social behaviour and without information relating to the person's neurotype (Sasson, Faso, Nugent, Kennedy, & Grossman, 2017). Indeed, autistic people are more likely to experience depression when they perceive reduced autism acceptance from others and experience reduced personal autism acceptance (Cage, Di Monaco, & Newell, 2018). This may reflect implicit and explicit attitudes towards autistic people, but also a broader societal tendency to pathologise, reject or ostracise 'individuals seen as a risk to productivity and conformity to normative standards' (Milton, 2013c).

The increased prevalence rate of mental health difficulties could also reflect a lack of adequate mental health support services for autistic people. Very few

specialist mental health services for autistic people exist, and mainstream services often lack professionals with adequate autism training (Dillenburger, McKerr, Jordan, & Keenan, 2016; Kinnaird, Norton, Stewart, & Tchanturia, 2019). The autism training for mental health professionals that does exist often lacks input from autistic people and is framed using deficit-based models. There are numerous barriers to autistic young people accessing mental health support (Crane, Adams, Harper, Welch, & Pellicano, 2019) and therefore many have unmet mental health support needs (Chiri & Warfield, 2012).

The four hypotheses presented above are not mutually exclusive; instead, they reflect the multiple factors contributing to the elevated rate of mental health difficulties experienced by autistic people. Twin studies in the general population show that genetic, shared-environmental and non-shared environmental factors can each play a role in explaining the covariance between autistic traits and co-occurring difficulties (Scherff et al., 2014). Different co-occurring mental health difficulties also differ in the extent to which different factors can explain the covariance. Genetic factors appear to have a stronger influence on the co-occurrence of autism and emotional difficulties whereas non-shared environmental factors have the greatest influence in the co-occurrence of autism and conduct problems (Tick et al., 2016). Further investigation is needed to understand the influence of the multiple factors involved in the relationship between autism and mental health, and the interactions between them (Lai et al, 2019).

The final hypothesis explored above, that autistic people experience more mental health problems due to experiences located within a social environmental context, can be further informed and developed by relatively new research into masking. Many autistic people report that they are unable to be their authentic

autistic selves in social situations, and over time, both consciously and unconsciously change their behaviour to present themselves as neurotypical (Hull et al., 2017). This process could be understood as a reaction to a social message that one's authentic autistic self is not acceptable. It is important to consider how masking interacts with environmental context and the development of mental health difficulties. I will now go on to summarise what is currently understood about masking, before returning to consider the complexities of the relationship between masking and mental health.

What is Masking?

Masking can be defined as the conscious and unconscious process of 'putting on an act', to appear non-autistic, in order to 'camouflage' or feel safe in a social setting (Dean, Harwood, & Kasari, 2017; Hull et al. 2017). Masking has been conceptualised in various ways; from a set of learnt social coping strategies to a complex, eventually unconscious, suppression of one's authentic self.

Masking is a relatively new construct which can also be conceptualised from a range of theoretical perspectives and is likely to reflect multiple processes and experiences. Aspects of masking may overlap or relate to existing constructs, such as self-monitoring (Henderson et al., 2015) or social anxiety (Hull et al., 2019). Elements of a cognitive conceptualisation of social anxiety (Clark & Wells, 1995), for instance self-focused attention, perceived (and actual) social danger, or safety behaviours, may also be relevant in understanding aspects of masking. Masking also relates closely to Goffman's (2009) concept of 'impression management' used by those with a 'spoiled identity' to avoid or respond to stigma. In line with this a Social Identity Theory conceptualisation of masking (Cage & Troxell-Whitman, 2019; Perry, Hull, Mandy, & Cage, 2020) highlights the impact of stigma, social norms and societal expectations on autistic people as members of a stigmatised and 'othered'

minority group, ultimately driving the need to conceal the stigmatised aspects of their identity.

Another theoretical consideration is that masking, at the conscious level, involves both introspection and an ability to predict the mental states of a neurotypical other, which puts the concept at odds with the mindblindness theory of autism (Baron-Cohen, 1995), as well as the theory of own mind deficit hypothesis (Williams, 2010). However, masking may be an important factor in understanding neurodivergent or autistic self-processing (Nijhof & Bird, 2019) and heterogeneity within this (Lai et al., 2019).

Terminology and definition

Existing literature has used a range of terminology to describe this concept, including masking, social camouflaging, compensation, and assimilation. In existing qualitative studies autistic people have used the term 'masking', as well as 'camouflaging', 'imitation', 'mimicking', 'compensation' and 'passing', among others, to describe their experiences (Hull et al., 2017; Bargiela, Steward, & Mandy, 2016; Tierney, Burns, & Kilbey, 2016; Cage & Troxell-Whitman, 2019; Raymaker et al., 2020).

Hull and colleagues (Hull et al., 2017; Hull et al., 2019), based on qualitative interviews and factor analysis of questionnaire data, breaks the construct of 'social camouflaging' down into three categories; compensation, masking and assimilation. Compensation is defined as finding ways around social communication differences, such as learning scripts for the 'right things' to say in different social situations, observing others and researching social rules. Masking is defined as hiding autistic traits, and presenting a non-autistic persona, for instance forcing oneself to make eye

contact and monitoring and adjusting facial expression and body posture to appear relaxed and interested in others. Assimilation is defined as using strategies to fit in during uncomfortable social situations, for instance forcing oneself to interact with others but feeling a strong sense of not being one's authentic self.

Livingstone, Shah, and Happé (2019) have described the construct of 'compensation', which they suggest could fall under the broader construct of social camouflaging. Shallow compensation is defined as learned behaviour aiming to facilitate social interaction, for instance forcing oneself to make eye contact, learning scripts or copying others. Deep compensation is defined as strategies that provide an alternative route to social cognition, for instance mentalising other's thoughts or feelings. This might involve learning the verbal and nonverbal cues of others, observing and assessing others behaviour and learning psychological theories of behaviour. Lai et al., (2019) acknowledge that the term 'compensation' is often used in neuropsychology to refer to strategies for bypassing cognitive deficits and therefore needs further consideration. The language we use has the power to shape reinforce or challenge dominant narratives of autism.

These frameworks and definitions are in their infancy, and the distinctions between constructs require further exploration. Lists of strategies or behaviours may fail to capture the extent and complexity of what it means to suppress one's autistic identity, therefore researchers must be led by autistic people to refine the terminology and definitions currently being used. Additionally, to the best of our knowledge, masking has only been researched with individuals without a learning disability, and therefore the experiences of autistic people who have learning disabilities and may also mask, are not yet understood.

In a recent social media campaign "Take the Mask off", led by four autistic advocates and participated in by thousands of autistic individuals, masking was the term used to explore a whole range of experiences relating to the suppression of the autistic self and presentation of the self as non-autistic. To best reflect the language most commonly used by the autistic community (for example; Rose, 2017; Holmans, 2018), as well as the participants in the current study, masking is the term used throughout this thesis.

The "female camouflage effect"?

It is widely recognised that autism may be under diagnosed in girls (Baird, Douglas, & Murphy, 2011). A meta-analysis of population prevalence studies has shown that females who meet the diagnostic criteria for autism are less likely to have received a diagnosis compared to males (Loomes, Hull, & Mandy, 2017). The female camouflage effect (Wing, 1981; Kopp & Gillberg, 1992) was originally proposed to explain gender differences in autism diagnosis prevalence.

Studies found that teachers were less likely to recognise female students who were experiencing social difficulties or presenting with social differences (Mandy et al., 2012; Dean, Harwood, & Kasari, 2017). It was proposed that that motivation and ability to imitate social interactions, allows autistic girls to mask their social difficulties and differences from others (Bauminger et al., 2008; Carrington et al., 2003; Gould & Ashton - Smith, 2011; Dean, Harwood, & Kasari, 2017). Indeed, in qualitative research studies, autistic adolescent girls described various ways they strove to hide their social difficulties and differences, including imitating their non-autistic peers (Tierney, Burns, & Kilbey, 2016).

As research interest has grown, it has become increasingly clear that masking is not only experienced by autistic people who identify as female. Moving away from discussing gender dichotomously promotes the inclusion of people of all gender identities; and a significant proportion of autistic people identify as a transgender or non-binary (Murphy, Prentice, Walsh, Catmur, & Bird, 2020; Van Der Miesen, Hurley, & De Vries, 2016). Masking has been observed in, and reported by, male and non-binary autistic adults and adolescents (Hull et al., 2017; Lai et al., 2017; Cassidy et al., 2018; Livingston, Shah, & Happé, 2019). The type of and amount of masking used is highly variable in all genders (Lai et al., 2017; Hull et al., 2017; Hull et al., 2019). Hull et al,. (2020) found that autistic women reported more masking and assimilation strategies, as measured by the Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019), than autistic men or non-binary people. However, autistic people of all genders reported similar amounts of compensation strategies. Overall, autistic females reported using more camouflaging strategies (Hull et al., 2019), however there are limitations to the measures currently being used to quantify camouflaging. The ways in which current research has operationalised and measured masking may not be capturing all aspects of what it means to mask. It is possible we are currently measuring how masking is most commonly seen and experienced in people identifying as female, and missing aspects of masking more common to people who identify as male or non-binary.

The relationship between gender, masking and age of diagnosis is also unclear. For instance, masking might prevent recognition and diagnosis of autism, but remaining undiagnosed for more years may push someone to put increasing effort into hiding their differences in a wider range of contexts. Autistic women are

often diagnosed later in life (Lai & Baron-Cohen, 2015) and it is not yet understood how this might mediate the gender differences in masking.

Research to date has not explored how the social cultural process of being gendered as female might make someone more likely to mask. It has been proposed that the socio-cultural environment may impose higher expectations on girls and women regarding social-communication and interaction. Girls and women may be under more pressure to conform to gendered social norms of interaction and communication (Kreiser and White, 2014; Lai et al., 2015), and this may influence how safe it feels to show social differences (Bargiela, Steward, & Mandy, 2016). It is important to consider how gender intersects with other aspects of identity or experience. For instance, autistic people and people with learning disabilities who are from Black, Asian and other racialised groups are more likely to be perceived as dangerous by the police (Abramov, 2017). Research has not yet explored how social injustices, such as racial prejudice, influence the pressure to mask and consequences of masking, or not. Intersectionality and social context must be considered in the effort to understanding the drivers and consequences of masking.

Measuring masking

Researchers have measured masking in various ways, which are outlined here.

Lai et al., (2017) first operationalised and measured masking using a discrepancy approach; the difference between a person's external behaviour in a social context, measured by the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000), and their 'internal' states, traits, and social cognitive abilities, measured by the Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright,

Skinner, Martin, & Clubley, 2001) and the 'Reading the Mind in Eyes' test (RMET; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001). This operationalisation was based on the notion that learnt behaviours such as imitation, gestures and conversation skills, which would be observed in the ADOS, mask the presence of a person's underlying differences or difficulties, which would be captured by the AQ and RMET. In other words, this approach attempts to capture an individual's experience of being autistic compared to what they portray externally. This approach does not capture the experiences of individuals who are experiencing a strong internal and external pressure to mask, and may be endeavouring to do so, but without success. Additionally, the AQ and RMET are proxy measures for some traits, difficulties and differences which may relate to the internal experience of being autistic for some individuals but not for others.

In light of these limitations, Hull et al., (2019) developed a self-report measure; the Camouflaging Autistic Traits Questionnaire (CAT-Q). An online study elicited qualitative descriptions of masking from 92 autistic adults (Hull et al., 2017). An exploratory factor analysis identified three factors; masking (e.g. monitoring body language or facial expressions to appear interested in others), compensation (e.g. copying other's body language or facial expressions) and assimilation (e.g. feeling as though pretending to be 'normal'). The 25 item CAT-Q was developed from these finding. One limitation of this approach is that qualitative research has taught us that masking often becomes unconscious over time. One adolescent explained, "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, Burns, & Kilbey, 2016, p. 19). The CAT-Q measure does not capture the complexity of this felt sense, and may

not pick up masking at all if an individual is no longer consciously using specific strategies.

As described above, masking has been defined and measured quantitatively in a number of ways by researchers. This work has been useful in beginning to operationalise masking, however quantitative measures are reductionist by nature. Reducing the process of masking to a set of strategies, or the difference between internal and external traits, risks overlooking and failing to understand the complex, idiosyncratic experience of masking part of one's identity, including the impact of this on the experience of the self and the world around us. We also lack an understanding of when and how masking might develop. It is important to consider which social experiences and narratives about autism or difference, are powerful in influencing someone, consciously or unconsciously, to start masking. The construction of a mask is surely a subtle and longitudinal process, unique for each individual, both influenced by and in turn influencing one's mental health. It is essential to hear autistic people's narratives of this complex process, particularly the experiences of autistic adolescents, in order to understand how the development of masking and mental health difficulties might influence one another.

Why do autistic people mask?

Autistic people have identified a number of factors which drive their experiences of masking. These factors have been broadly summarised under the following headings:

Impression Management

Masking has been compared to the broader concept of impression management and certainly, autistic people have reported concerns about the

impression they make when not masking (Cage & Troxell-Whitman, 2019). 'Putting on an act' is an experience most non-autistic individuals find they can relate to; for instance, publicly agreeing to a majority opinion or having different personas at work, with friends or with family. It has been suggested that masking describes the way all people try to fit in and hide less socially desirable parts of their personality and as one autistic man put it "most neurotypicals are camouflaging nearly all the time they are in public" (Hull et al., 2017, p. 2524). Hull et al., (2019) found that, non-autistic people report using masking strategies (measured using the CAT-Q) but less so than autistic people, even after controlling for 'autistic like traits'. Although the types of strategies used by autistic people in the process of masking may not be uniquely used by autistic people, it has been hypothesised that the reasons for masking, the energy and effort involved in the experience and the consequences of masking are what make it such an important factor in understanding many autistic people's experiences. Evidence that autistic people conform less than non-autistic people in social influence experiments (Yafai, Verrier, & Reidy, 2014) further suggests that masking might be motivated by something more than impression management or pressure to conform.

Social connection

The Double Empathy problem describes the difficulties non-autistic and autistic people may experience in attempting to understand each other's sociality. Milton (2012) points out how non-autistic people are not expected to invest time or energy into understanding and adapting to the world-view of autistic people. With the responsibility primarily falling to autistic people to adapt to a neurotypical sociality, masking may be deemed necessary in order to form connections and friendships cross-neurotype. Certainly, autistic people desire meaningful social

connections, and to feel socially accepted (Jaswal & Akhtar, 2019; Cage, Bird, & Pellicana, 2016), and one motivation for masking that autistic people report is 'to know and be known' (Hull et al., 2017). Some autistic people have described how 'connections have to be made initially on neurotypical terms' (Hull et al., 2017, p. 2525) in order to make friends, appear likable or bond with non-autistic others. This may be driven by the pressure of the potential consequences of not masking, for instance 'What if I can't make friends? I'm going to have to make sure that I'm always perfect for everyone' (Tierney, Burns and Kilbey, 2016, p. 18).

Assimilation

Autistic people have also described how masking develops as a way to blend in with non-autistic others and to hide signs of difference or difficulty (Hull et al., 2017). Masking has been described as a response to social pressure to act in a socially normative way, or to 'pass' as neurotypical (Cage & Troxell- Whitman, 2019). For instance, in workplace or educational contexts, acceptance and success may seem, or be, contingent on fitting into the expected social mould and not standing out as different. Some autistic people have described how this requires the careful development of a different persona, with neurotypical interests or habits (Bargiela, Steward, & Mandy, 2016).

Autistic people have described the experience of feeling like a minority, in the presence of neurotypical people, and this being the driver to behave like a neurotypical person during these interactions. Some autistic people have also described how interactions with other autistic people do not elicit this experience of minority stress, and therefore the pressure to mask is eliminated or much reduced (Crompton, Fletcher- Watson, & Ropar, 2019).

Shame

Shame can also be an emotional driver of masking for autistic people. Shame is an emotion which comes from experiencing oneself as held negatively in the minds of others. In current society, autistic traits are labelled as a 'deficits' (APA, 2013), groups of researchers and clinicians still aim to find and use 'treatments' and 'cures' (e.g. Farmer, Thurm, & Grant, 2013), and autistic people perceive low levels of autism acceptance within society (Cage, Di Monaco, & Newell, 2018). It is therefore unsurprising that autistic people are vulnerable to internalising this stigma and that masking develops as an attempt to reduce shame and to feel 'good enough' (Cage & Troxell- Whitman, 2019).

Safety

Autistic people report significantly more experiences of bullying than non-autistic people (Maiano, Normand, Salvas, Moullec, & Aimé, 2016). Past experiences of bullying, prejudice and discrimination lead autistic individuals to hide the parts of themselves it no longer feels safe to share with the outside world (Cage & Troxell- Whitman, 2019). Masking has been identified as a protective strategy in avoiding prejudice and discrimination in employment or education (Hull et al, 2017). As one person described, "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" (p. 2525).

Masking one's identity has been described as a protective strategy by people from other minoritized groups. Rodriguez (2016) writes, "Masking our inner selves serves as defences against racist educational institutions in which we try to manoeuvre through. We construct a certain persona in public, through the clothes we

wear, the way in which we speak, and so on". Edwards (1996) describes the hiding of one's sexual orientation as 'a form of self-preservation', a process which Martin (1982) identifies as involving great deal of time, energy and monitoring of the self in social contexts. Being a member of a minoritised group, in a society rife with social inequality, provides a context in which gradually suppressing and hiding stigmatised parts of one's identity is an innate response to threat.

Being undiagnosed

Masking has been proposed as an account for missed or late diagnoses (e.g. Lai and Baron Cohen, 2015), however it may also be true that late diagnosis drives masking as it becomes more and more habitual. ''I honestly didn't know I was doing it [social mimicry] until I was diagnosed, but when I read about it, it made perfect sense. I copy speech patterns and certain body language.'' (Bargiela, Steward, & Mandy, 2016, p. 3287, Participant 9). Without an explanation or understanding of why one's sociality, perceptions or interests for instance, are 'different', it may be that the authentic self becomes increasingly hidden.

What are the mental health consequences of masking?

Research findings have begun to explore the impact masking can have on autistic people's mental health.

Stress and anxiety

Autistic people have described the anxiety and stress experienced while masking. Sometimes this relates to the pressure of masking successfully, which involves the stress of closely monitoring of one's own behaviour and predicting the reactions of others (Hull et al., 2017; Livingston, Shah and Happe, 2019). Masking involves the suppression of autistic traits, which can include self-stimulatory

behaviour, or 'stimming'. Autistic people stim in order to regulate anxiety, especially in environments which are sensory overloading (Lipsky, 2011). The suppression of stimming therefore involves the loss of a key emotional regulation strategy. Autistic people have also described the anxiety experienced after masking. This sometimes involved going back over the interaction and analysing what was said, if 'mistakes' were made, if anyone was offended and if the masking was 'successful' (Hull et al., 2017; Livingston, Shah and Happe, 2019).

Using the existing tools to quantify both masking and anxiety, studies have found that autistic people who mask more, also report experiencing higher levels of anxiety (Cage & Troxwell Whitman; 2019, Hull et al., 2019; Livingston, Colvert, Social Relationships Study Team, Bolton, & Happé, 2019). Conversely, two studies did not find a relationship between compensation and anxiety (Lai et al., 2017; Schuck, Flores, & Fung, 2019). It may be that the discrepancy method of measuring masking does not best capture the aspects of the experience which most relate to anxiety.

Burnout and exhaustion

Conscious masking can require intense concentration, self-control, and management of pain and discomfort (Hull et al., 2017). This substantial cognitive and emotional effort can lead to exhaustion and burnout. Autistic burnout is just recently being explored in academic studies (Raymaker et al., 2020), and it is often missing from clinician training and resources, however it has been described by numerous autistic adults (Endow, 2015; Boren, 2017; Rose, 2018). Autistic burnout has been described as 'an accumulation of years of trying to appear normal and cope as a neurotypical. The strain and drain of it suddenly becomes too much and a person

with autism falls apart' (Endow, 2015). Boren (2017) explains how 'wearing the mask of neurotypicality drains my batteries and melts my spoons'. Mental, physical and emotional exhaustion have been frequently reported as a key consequence of masking (Hull et al., 2017; Tierney, Burns, & Kilbey, 2016; Bargiela, Steward, & Mandy, 2016; Livingstone, Shah, & Happe, 2019; Cage, Di Monaco, & Newell, 2018).

Depression

Some existing research suggests that people who self-report masking are more likely to report experiences of depression (Cage, Di Monaco & Newell, 2018; Hull et al., 2019). However, this finding has not been consistent; one study found an association between masking and depression in autistic men but not autistic women (Lai et al., 2017) and another study found no relationship between masking and depression (Cage and Troxwell Whitman, 2019).

In qualitative studies, participants have described how masking can lead to experiences of depression through isolation, low self-esteem and rumination on 'social failings' when masking was perceived to be ineffective (Livingston, Shah & Happe, 2019).

Loss of identity

Autistic people have described how masking one's autistic self can lead to overwhelming uncertainty about 'who I really am', often described as an identity crisis (Hull et al., 2017; Tierney, Burns, & Kilbey, 2016; Bargiela, Steward, & Mandy, 2016). After masking for many years, or as masking become unconscious or automatic, it can become extremely difficult for someone to differentiate between when they are masking and when they are being their 'true selves'. This is particularly the case for undiagnosed autistic people, who may not have made sense

of the parts of their identity they are trying to conceal. For people with a diagnosis, masking can lead to self-doubt, or comments from others, about whether they were 'really' autistic (Bargiela, Steward, & Mandy, 2016). This doubt creates further confusion about one's true self; 'I feel as though I've lost track of who I really am, and that my actual self is floating somewhere above me like a balloon' (Hull et al., 2017, Female 22, p. 2529).

Autistic people have described how masking can instil a feeling of inauthenticity (Hull et al., 2017). Emotionally this experience can evoke guilt about deceiving others or 'letting down' other autistic people, and anger at having to suppress one's, personally valued, autistic self.

Social isolation and disconnection

Masking can also have a serious impact on the quality of one's relationships. The sense of 'playing a part' or 'putting on a performance' often meant individuals did not feel, and were not, seen or known by others (Hull et al., 2017). Some autistic people have reported that masking impairs genuine connection during interactions and relationships, and instead leads to dissatisfaction and further isolation (Hull et al., 2017; Livingston, Shah and Happe, 2019).

Suicidality

Masking has also been identified as a predictor of suicidality in autistic adults (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018) and in qualitative studies autistic people have made direct links between masking and suicidal ideation (Livingston, Shah & Happe, 2019). Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy (2019)'s qualitative study found that a lack of appropriate treatment and support impacted autistic adult's suicidality. One of their participants described 'I see now

that I had never learned how to ask for help. I'd spent my life camouflaging and thought I had to be able to do it all myself' (p. 8). It has not yet been explored empirically if and how the relationship between masking and suicidality may be mediated by any of the other factors outlined above.

Are there any positive consequences of masking on mental health?

Some studies have reported benefits of masking for some autistic people; for instance, improved confidence or 'skills' in social situations, and accessing valued roles in work or educational settings (Livingston, Shah and Happe, 2019, Hull et al., 2017). However, in light of the findings above which highlight the many negative emotional consequences and risks associated with masking, the current evidence base is not in support of autistic people being encouraged or supported to develop masking strategies.

Indeed, it can be argued that encouraging autistic people to develop 'compensation' or masking strategies, reinforces the harmful status quo of a deficit-based narrative of autism, and an expectation that it is the responsibility of autistic people to adapt and assimilate during cross neuro-type social interaction (Milton, 2012). In Livingston, Shah and Happe's (2019) study, a participant described how, '"The worst aspect of my compensation techniques is that they work on the basis that I am not good in social settings and so by acting out my compensation techniques I reinforce this idea that I am bad at socialising and [this] lowers my confidence" (p. 772). When masking is, even in part, a response to bullying and discrimination, the ethical intervention is not to encourage the minority group work harder to gain acceptance. Autistic professionals who work in health and social care professions have spoken out on this issue; "I know in the field of autism we have made it our goal to get autistics to look neurotypical as we hold that as the prized norm. Many

people congratulate themselves when it happens. I am here to tell you (just as countless others from my tribe have done) that this may NOT wind up to be a good thing for autistic people" (Endow, 2015).

Understanding the relationship between masking and mental health

Research to date has revealed a relationship between mental health and masking, however we do not currently understand the mechanisms than underpin this relationship. A better understanding of the relationship between mental health and masking is needed, as this could potentially inform the development of improved psychological therapies for autistic people.

Conclusions about the directionality of the relationship between masking and mental health cannot be drawn from the existing research, however, a bi-directional link seems possible. For example, perhaps experiencing higher levels of anxiety, both consciously and unconsciously drives individuals to mask, however masking is a stressful experience, and is likely to trigger further anxiety. It may also be that for some, masking functions as a safety seeking behaviour (Salkovskis, 1991) in the context of poor autism acceptance, and that masking reduces anxiety in the short term but maintains the fear of the mask 'slipping' in the long run. As one participant explained, "As the years pass I suffer increasing anxiety for lack of even casual acceptance by my species and, conversely, huge spikes of anxiety when someone actually does 'see' me. Invisibility has become my comfort zone as well as my prison" (Cage, Di Monaco, & Newall, 2018).

Several theories and explanatory factors have been proposed thus far.

The social model of disability

Cage, Di Monaco, & Newell (2018) applied the social model of disability to thinking about autism acceptance, masking, and mental health. The social model of disability (Shakespeare, 2006) identifies the systemic barriers, societal attitudes and social exclusions, which prevent people with physical, psychological or neurodevelopmental differences from reaching or accessing desired roles, functioning or goals.

Therefore, while an autistic person may experience difficulties in relation to their autistic traits and neurology, this is only disabling due to a lack of societal autism acceptance and exclusionary or discriminatory practices. Autistic people who report masking also report more symptoms of depression and lower perceived autism acceptance (Cage, Di Monaco, & Newell, 2018). Social factors, including a lack of autism acceptance and experiences of alienation and bullying, appear to both drive and reinforce masking. One hypothesis is that the impact of social and environmental experiences on mental health is mediated by masking; for instance, bullying might have the most profound impact on mood or suicidality, when it leads someone to start masking aspects of their identity. It also possible that the impact of societal factors on masking is mediated by mental health, for example perhaps discrimination and rejection lead to higher levels of masking, due to the negative impact these experiences have on mental health which in turn drives masking. More research is needed to explore some of these hypotheses.

Suppression of emotional expressivity

Emotional expressivity is the strength of an emotional impulse and it is valence (positive or negative) (Gross & John, 1997). Schuck, Flores, & Fung (2019) found that autistic women who mask more (measured using the discrepancy method) showed lower emotional expressivity overall and lower positive emotional

expressivity. It may be that autistic people who mask more, are also masking their emotional responses. It could also be that autistic people express less positive emotions as a direct a consequence of the cognitive and emotional effort of masking, and this has negative consequences mental health.

Autistic burnout

As described about masking can lead to exhaustion and burnout. In turn exhaustion and burnout from masking may lead to the development of other mental health difficulties (Cage, Di Monaco & Newell, 2018; Gould and Ashton Smith, 2011). For instance, if someone has very limited opportunities to 'unmask', burnout and exhaustion might precede the development of further mental health difficulties, if appropriate support, understanding, and rest do not occur.

A lack of appropriate support

Autistic people have reported that those around them often do not realise they are masking their difficulties, and this can mean that support is not offered when needed (Hull et al., 2017; Tierney, Burns, & Kilbey, 2016, Bargiela, Steward, & Mandy, 2016). Masking can be an extra barrier to someone accessing help, particularly when professionals lack an understanding of masking, which could lead to worsening mental health difficulties.

Minority Stress Model

Masking can be understood as part of a wider profile of experiences relating to being an identity-based minority. Botha and Frost (2018) found that minority stressors, including masking, discrimination and internalised stigma, predicted poorer mental health in autistic adults.

What is the relationship between masking and mental health for autistic teenagers?

There is still much we do not know about when and how masking develops, or how it begins to impact upon mental health. Research into the consequences of masking on mental health has mostly focused on autistic adults. An exception to this, Livingston, Colvert, Social Relationships Study Team, Bolton, and Happé (2019), found that autistic teenagers who were rated as 'high compensators' more also reported experiencing more anxiety. We know that 50% of mental health difficulties develop by age 14, and 75% by aged 24 (Kessler, Berglund, Demler, Jin, Merikangas, Walters, 2005). It is therefore important to consider how young autistic people experience the development of mental health difficulties alongside the development of masking, and how the two impact each other.

The Current Study

More research is needed with autistic young people in order to understand the development of the relationship between masking and mental health earlier in the life span. In qualitative research studies autistic adolescents have described masking developing within the context of increasing social pressures, expectations and stressors of the school social and physical environment alongside an increased awareness of their social differences (Tierney, Burns, & Kilbey, 2016). Indeed, the transition to secondary school has been identified as a particularly challenging and stressful time for autistic young people and their families (Tobin et al., 2012). Autistic adults have identified specific experiences from adolescence which influenced the development of masking, for instance bullying and ostracism (Hull et al., 2017). It is important to hear more first-person accounts from autistic adolescents

about the contexts and experiences driving their experiences of masking and how this relates to their mental health.

Existing research has demonstrated a clear statistical relationship between masking and mental health. However, causation cannot be inferred from correlation, therefore much is still unknown about the development and underpinnings of this relationship. Qualitative data eliciting autistic young people's narratives about how masking develops and how this relates to their mental health will be key to deepening current understanding.

The current study will use take a qualitative approach. Twenty semi structured interviews will be conducted with autistic teenagers to explore their social experiences, elicit descriptions of masking, and discussions about the relationship between masking and mental health. Overall, the aim of the present research is to build on what is currently understood about the relationship between masking and mental health, focusing on the experiences of autistic teenagers.

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Part II: Empirical Paper

The relationship between masking and mental health for autistic teenagers: a qualitative study

Abstract

Aims: Previous research has identified an association between masking and mental health, for autistic people. However, the direction of causality and mechanisms involved in this relationship are not well understood. This study aimed to investigate autistic teenager's experiences of masking, mental health and how the two develop and interact.

Method: Twenty autistic teenagers took part in a semi-structured interview. The interviews were analysed using thematic analysis (Braun and Clark, 2006).

Results: From the analysis, one theme was identified to conceptualise masking as described by participants. Five more inter-related themes were identified, each involved both in the relationship between masking and mental health and conversely in the relationship between mental health and authenticity. The relationship between masking and mental health was described as bi-directional and was influenced by social and environmental factors.

Conclusions: The findings are consistent with previous research indicating a relationship between masking and mental health. Results describe a broader conceptualisation of masking than previously defined in the literature. They place social oppression at the heart of the relationship between masking and mental health. Results have implications for diagnostic services, post-diagnostic support, therapeutic interventions and highlight the need to challenge deficit-based narratives of autism.

Introduction

Autism represents one form of neurodivergence[1] and is characterised by differences in social communication, sensory, cognitive and emotional processing, sociality and interests (American Psychiatric Association, 2018). Using current diagnostic tools and conventions, prevalence rates suggest that 1.1% of people living in the UK are autistic (Baird et al., 2006; Brugha et al, 2009; Brugha et al, 2012). However. it is well documented that current diagnostic tools are less sensitive to diagnosing women and girls, and people with higher cognitive abilities, and so it is possible that these prevalence figures are underestimates of the true proportion of the population who are autistic (Kirkovski, Enticott, & Fitzgerald, 2013; Ratto et al., 2018).

Across the life span, autistic people are more likely to experience mental health difficulties than non-autistic people (Lai et al., 2019; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Mazzone et al., 2013; Rai et al., 2018). Simonoff and colleagues (2008) assessed the prevalence of mental health difficulties in a population-derived sample of autistic adolescents, aged 10 to 14, and found that 70%

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[1] Neurodiversity is a non-pathologising term, originally coined by Judy Singer in 1988, used to describe the wide variety in neurological profiles found within the human species. Someone who is 'neurodivergent' has a brain that functions in ways that diverge significantly from the dominant societal standards of 'normal' (Walker, 2014). Silberman (2016) argues for autism to be recognised as a form of neurodivergence; characterised by difference not deficit. The autistic rights movement supports the recognition of autism as a form of neurodivergence. There are controversies and differing ideas about how autism should be conceptualised (Baron-Cohen, 2019). Milton (2019) argues that differing opinions must not prevent 'interactional expertise' being developed where autistic people can lead and co-produce on meaningful research.

were experiencing at least one mental health difficulty. Varying explanations have been proposed to make sense of these findings.

One explanation highlights the overlap between autistic traits and experiences of mental health difficulties, for instance social anxiety (Cath, Ran, Smit, Van Balkom, & Comijs, 2008). This explanation is weakened by evidence that overlapping traits are superficial and empirically distinguishable from one another (for example; Kleberg and colleagues, 2017). Another explanation of the high co-occurrence of autism and some mental health difficulties is that they share common underlying causes. In support of this idea, research has identified some overlapping genetic and neural underpinnings of autism and some mental health difficulties (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013; Hollocks and colleagues, 2014), however these are not clearly understood and do not fully explain the association between autism and diverse mental health difficulties (Rylaarsdam, & Guemez Gamboa, 2019).

Another hypothesis is that the experience of being autistic, or having autistic traits, has a direct impact on one's mental health. For instance, autistic traits such as sensory processing differences could make one's experience of the word innately more stressful and anxiety-provoking (Ozsivadjian, Knott, & Magiati, 2012). Indeed, sensory sensitivities, alexithymia (difficulties identifying and describing feelings) and social communication differences are each associated with an increased chance of experiencing mental health difficulties (Tseng, Fu, Cermak, Lu, & Shieh, 2011; Milosavlijevic et al., 2016; Rai et al., 2018).

Another avenue of explanation has considered autism as an indirect risk factor for mental health difficulties. This posits that autistic people's increased

chance of experiencing mental health difficulties is mediated by social,

environmental and contextual factors. Such an approach is in line with the social

model of disability (Shakespeare, 2006), as it seeks to move away from locating

problems within individuals and instead seeks to describe how external, social

factors are often the root of disabling experiences. This can be applied to the mental

health experiences of autistic people. Autistic people, across the lifespan, are more

likely to have experienced victimisation, bullying, trauma and a range of other

stressful life events (Griffiths and colleagues, 2019; Berg, Shiu, Acharya, Stolbach,

& Msall, 2016). Experiences of bullying mediates the association between social

communication difficulties and depression (Rai et al., 2018). It appears that non-

autistic people's attitudes and behaviour towards autistic people also impacts mental

health. Autistic people who experience depression perceive lower autism acceptance

from others and have lower personal autism acceptance (Cage, Di Monaco, &

Newell, 2018). Milton (2013) describes the broad societal tendency to pathologise

and ostracise people who do not conform to social normative standards and the

oppressive impact this has on autistic people.

Masking, or 'social camouflaging', may be another important factor in

understanding why autistic people are more likely to experience mental health

difficulties and particularly how this is mediated by the social and environmental

context. Autistic people have described experiences of suppressing aspects of their

authentic, autistic selves in social situations, and of 'putting on an act' to present

oneself as neurotypical (Hull et al., 2017). Masking may represent a direct

manifestation of social and environmental stressors or a response to these stressors.

Masking can involve deliberately and consciously using specific strategies, for instance self-monitoring body language and facial expressions, developing a 'script' for social situations, or forcing oneself to make eye contact (Hull et al., 2019). However, accounts also suggest that masking can also develop and be maintained subconsciously. For instance, autistic people diagnosed in late adolescence or adulthood have described masking unconsciously when undiagnosed (Bargiela, Steward, & Mandy, 2016). Furthermore, some autistic people have emphasised how masking can become so automatic and pervasive while navigating 'the neurotypical world' that aspects of one's identity can become confusing, and it can feel unclear even to the individual where the mask begins and ends (Tierney, Burns, & Kilbey, 2016; Bargiela, Steward, & Mandy, 2016; Hull et al., 2017).

Masking is driven by multiple concerns for autistic people. Masking can develop as a protective mechanism to avoid re-experiencing bullying, rejection, discrimination or ostracism (Cage & Troxwell-Whitman, 2019; Hull et al., 2017). Autistic people who report more masking, are less likely to report experiencing acceptance from others (Cage, Di Monaco, & Newell, 2018). Autistic people have explained masking as a search for acceptance from others (Cage, Di Monaco, & Newell, 2018), which may also be driven by shame and self-criticism (Cage & Troxell- Whitman, 2019). Masking can be driven by a sense, often based on negative past experiences, that friendships and connections, particularly with non-autistic others must be made 'on neurotypical terms' (Hull et al., 2017). Masking can also be motivated by a social pressure to fit in, assimilate or 'pass' as neurotypical in a social situation (Bargiela, Steward, & Mandy, 2016, Hull et al., 2017; Cage & Troxell-Whitman, 2019).

Existing research has begun investigating the mental health consequences of masking. Autistic people who mask more also report higher levels of anxiety (Cage & Troxwell Whitman; 2019, Hull et al., 2019; Livingston, Colvert, Social Relationships Study Team, Bolton, & Happé, 2019), and some studies have also found an association between masking and depression (Cage, Di Monaco & Newell, 2018; Hull et al., 2019). Although these findings strongly suggest there is a correlation between masking and mental health difficulties, the direction of causality cannot yet be inferred.

In qualitative studies, fears of being bullied, victimised, ostracised or rejected are described as driving the need to mask (Bargiela, Steward, & Mandy, 2016; Hull et al., 2017; Cage & Troxell-Whitman, 2019; Livingstone, Shah, & Happe, 2019), as well as anxieties about appearing different, not fitting in or making 'social errors' (Bargiela, Steward, & Mandy, 2016; Tierney, Burns, & Kilbey, 2016; Hull et al., 2017; Cage & Troxell-Whitman, 2019). Masking, within itself, has been described as stressful and anxiety provoking, particularly in relation to fears relating to be 'found out' or 'getting it wrong' (Bargiela, Steward, & Mandy, 2016; Hull et al., 2017).

Masking is described as mentally, physically and emotionally draining, and burnout and exhaustion have been identified as both short and long-term consequences (Hull et al., 2017; Tierney, Burns, & Kilbey, 2016; Bargiela, Steward, & Mandy, 2016; Livingstone, Shah, & Happe, 2019; Cage, Di Monaco, & Newell, 2018). Of serious concern is that masking has also been identified as a predictor of suicidality in autistic adults (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018).

Autistic people have described masking having a negative impact on self-esteem due to perceived social failings and ineffective masking (Livingston, Shah &

Happe, 2019). Masking can also lead to a sense of identity confusion relating to a loss of 'authentic self' (Hull et al., 2017; Bargiela, Steward, & Mandy, 2016; Tierney, Burns, & Kilbey, 2016), and a disconnection from other people (Hull et al., 2017; Livingston, Shah and Happe, 2019).

Aims of the current study

Existing research has strongly indicated that there is a relationship between masking and mental health difficulties, however the direction of causality and the mechanisms involved in the relationship are not yet understood. The majority of masking research to date has focused on autistic adults. The process of when and how autistic children and young people may begin to mask, and how this interacts with the development of mental health difficulties, has not yet been investigated.

A challenge of investigating the development of masking in teenagers, while they are still navigating the developmental stage of adolescence, will be making sense of how autistic masking may develop within or alongside typical adolescent social identity processes. However, to understand how masking might develop within this developmental stage, and particular social context, it is essential to hear autistic teenager's narratives and lived experiences of the process. This is particularly important as existing qualitative research has indicated that adolescent experiences and contexts, such as bullying, school transitions and increasing neurotypical social pressures and expectations, are involved in the development of autistic masking which continues into adulthood (Tierney, Burns, & Kilbey, 2016; Hull et al., 2017). Autistic adults also report 'habit' (Cage and Troxwell-Whitman, 2019) as a reason for camouflaging, which related to being taught or conditioned to see social

differences as being 'bad' as a child. It is important to understand this from the perspective of autistic young people.

Qualitative research can help to develop a more detailed understanding of people's experiences and how they make sense of them. It can generate a richer understanding of the mechanisms that may underly a relationship between two phenomena. Although qualitative methods are limited in their ability to make conclusions regarding causality, they are a particularly helpful tool for enriching understanding in newer areas of research by generating ideas and hypotheses which can be tested by further research in the future. Therefore, the present study takes a qualitative approach to investigating the relationship between autistic teenager's experiences of masking and their mental health. Autistic teenagers' social experiences will be explored to elicit descriptions of how masking and mental health influence one another.

The key research questions were:

1. How do autistic teenagers describe their experiences of masking?
2. How do autistic teenagers describe the relationship between their experiences of masking and mental health?

Method

Expert by experience involvement

This study was informed throughout by regular consultation with an autistic advocate, writer and trainer, with expertise in autistic people's mental health and their experiences of masking. Prior to joining the current project, our expert by experience led an international social media campaign 'take off the mask', and the

stories and experiences shared in this campaign provided many insights and ideas which contributed to the design of the current study. Our expert by experience also reviewed and provided comments on the project proposal, interview schedule and initial themes, to ensure they felt valuable and appropriate. All were refined in response to their comments.

Participants

Eligibility criteria. Autistic teenagers (age = 13-19) who had received a diagnosis of Autism Spectrum Disorder (including Autism, Asperger's Syndrome, High Functioning Autism, Pervasive Developmental Disorder) from an appropriate professional, and did not have a learning disability diagnosis (IQ of 70 or above), were eligible to take part in the study.

Recruitment. Participants were initially recruited for an earlier quantitative phase of this project (see Appendix A for joint working statement). For the earlier phase, families were contacted via NHS services, voluntary sector organisations, and social media. Participants from phase one, who had indicated they were happy to be re-contacted, were emailed with information about the current study. Thirty-five families were emailed an invitation to take part, and 27 responded. Out of these 27 families who initially responded, five did not respond to follow up emails, one dropped out prior to the interview due to mental health reasons and one was turned down when the sample size needed for males was reached.

Demographic information. Twenty autistic teenagers (age range = 13-19, mean = 15 years old) living in multiple regions across England participated in this study. Ten participants identified as male and ten identified as female. Twelve

attended a specialist school or college for autistic young people, seven attended a mainstream school or college and one was home-educated.

Procedure

Seventeen out of twenty of the interviews took place face to face in the participants home, one took place face to face at a university research lab and two took place over a video call. All interviews were digitally recorded and lasted an average of 45 minutes (range: 17-73 minutes).

Teenagers and their parents were sent separate information sheets (Appendix B) in advance, were given opportunities to ask questions and signed individual consent forms (Appendix C). Teenagers were reminded of their right to withdraw at any time. A visual stop and pause prompt was placed on the table, giving teenagers the option to indicate visually, rather than verbally, that they would like to stop the interview if necessary. Gender pronouns (e.g. he / she / they) and preferred language regarding autism (e.g. autistic person / person with autism) were also confirmed and used accordingly throughout the interview.

Following each interview, a short debrief took place with the teenager, and where appropriate their parent, to discuss the research topic, the teenager's experience of the interview and signposting for further support where necessary.

Semi-Structured Interview. The semi-structured interview schedule (Appendix D) was developed in consultation with other researchers and the project's expert by experience, and drawing on best practice guidance (Barker, Pistrang, & Elliott, 2016). It was guided by existing research into the conceptualisation of masking and its relationship with mental health (Hull et al., 2019), although care was

taken not to assume that teenager's experiences of masking would mirror adult's experiences.

The interview schedule included questions about social experiences and presented an opportunity for participants to spontaneously speak about masking without being directly asked about the pre-defined concept. Later in the interview, masking was asked about directly, using a range of descriptions from the existing literature. Participants were asked about the cognitive, physical, emotional and behavioural experience of masking, their mental health experiences and about the relationship between masking and their mental health experiences.

In line with good practice guidance (Barker & Pistrang, 2005), the interview schedule was piloted in the early interviews, refined accordingly and used in all subsequent interviews. From this process, questions were added about how experiences of diagnosis impacted experiences of masking and mental health. Clarifying questions were also added about the differences between social experiences with autistic and non-autistic others. Finally, follow up questions were added to ask about social messages participants had been influenced by from wider society and their social environment.

Qualitative Data Analysis

Interviews were transcribed verbatim and anonymised. Transcripts were analysed using a Thematic Analysis approach, to identify, analyse and report themes within the data (Braun and Clark, 2006). Researchers were keen to recruit, in qualitative research terms, a relatively large sample in order to hear from both males and female participants at different stages of adolescence. Thematic analysis was identified as a systematic and flexible method which would allow researchers analyse

a large amount of data. As the research topic is in its infancy, an inductive, data-driven approach was chosen, in order to capture participants experiences and how they have made sense of them, in order to generate hypotheses about causality which could be tested in the future. During the process of analysis, the researcher took a critical realist approach (Willig, 1999), to allow for consideration of how the broader social context was impacting upon the participant's experiences and the meanings they were making.

Braun and Clark's (2006) six step guide to doing thematic analysis was followed. The twenty transcripts were read through in full prior to starting coding and initial ideas for coding were noted. Initial codes were then generated for the entire dataset, and these codes were then sorted into potential themes. A preliminary thematic map, of initial themes and sub themes, was developed (see Appendix E). These initial themes were discussed and refined with two other researchers, particularly considering internal homogeneity and external heterogeneity (Patton, 1990). The researcher then returned to the data, firstly the coded extracts and then the entire data set, to review and rework the themes, before the final themes and subthemes were defined and named. Finally, the analysis was written up, using extracts from the data to support each theme. The numbers of participants who spoke about each subtheme are also given within the write-up, to demonstrate how commonly each one came up in the interviews.

Credibility checks. Good practice guidelines (e.g. Barker & Pistrang, 2005) were followed to strengthen the credibility of the findings. A consensus approach was used throughout. The main researcher met with two other researchers three times during the analysis process, to share early iterations of the thematic map and to discuss different ways of grouping and presenting the themes. One of the researchers

also read and coded exerts of interviews. Differences in coding were discussed and a consensus reached.

Disclosure of perspective

I am a 27-year-old, white British, cisgender, able-bodied, bisexual woman. I am a non-autistic person, who through the process of this project has become aware of some of my own neurodivergent traits. I have close relationships with autistic friends and family members and have worked in mental health settings supporting autistic children, young people and adults. My experiences, and aspects of my identity, have led me to develop strongly held values about the differences between people being accepted and celebrated, and individuals being safe and supported to be their authentic selves. This perspective cultivated my interest in the current project and throughout I have reflected on how this has impacted upon my approach to the research and my assumptions about the relationship between masking and mental health. Regular conversations with my supervisors and peers have supported me to remain aware of my perspective and to avoid shutting down possible areas of enquiry or understanding.

Ethical Approval

Ethical approval (see Appendix F) was obtained from the NHS Health Research Authority Ethics Committee, the UCL/UCLH Joint Research Office, Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, the Whittington Hospital NHS Trust and East Kent Hospitals NHS Trust.

Results

Overview of findings

The analysis generated six themes. Figure 1a and 1b present a map of these themes and shows processes identified firstly in the relationship between masking and mental health and conversely in the relationship between authenticity and mental health. These two processes are not distinct, but rather are 'two sides' of the same overarching thematic map. Through the analysis, pathways were identified for how mental health related experiences can drive masking or authenticity, and how experiences of masking or authenticity had further consequences for mental health. The majority of participants had experiences of both pathways, or aspects of both pathways.
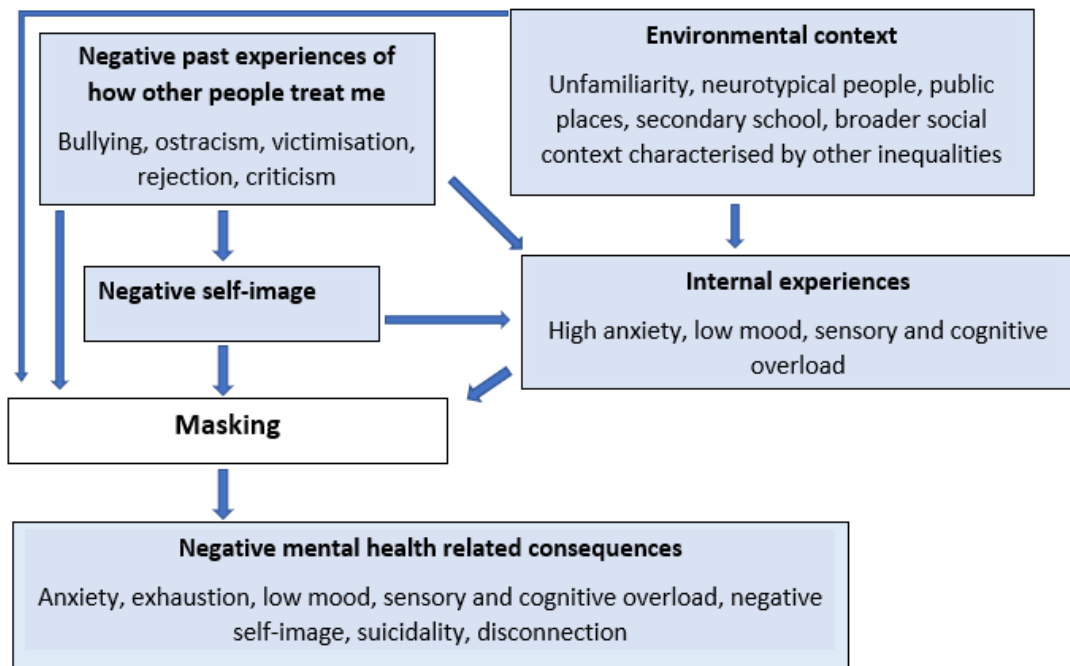
Figure 1a. Development of relationship between masking and mental health
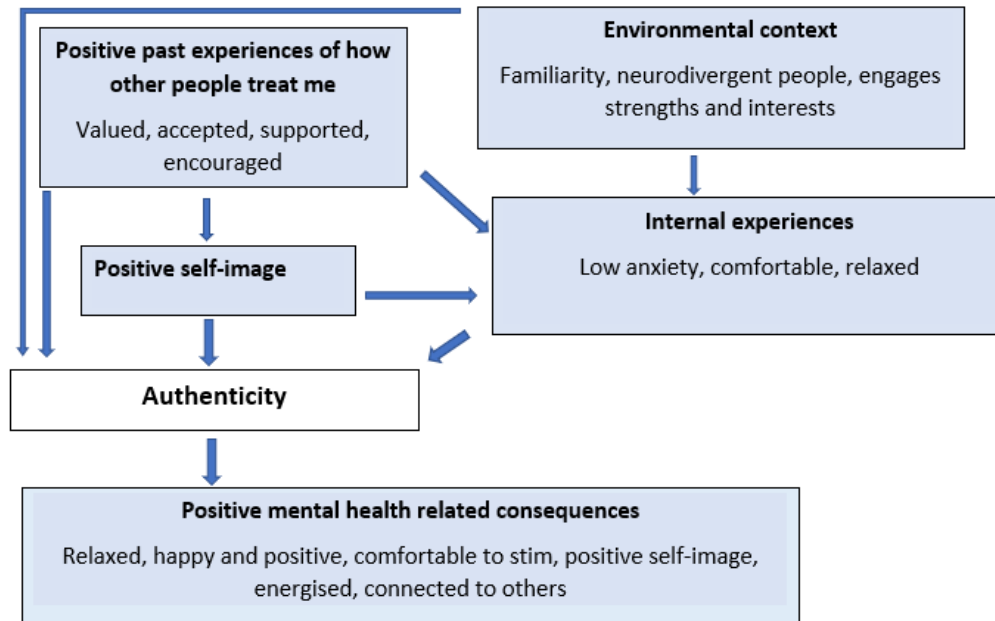
Figure 1b. Development of relationship between authenticity and mental health

All themes and subthemes are listed in Table 1. The theme 'What is Masking?' describes how masking was conceptualised by participants and 'Authenticity' describes participants experiences of not masking and, instead, being able to be their true selves. All subsequent themes represent other factors involved in the relationship between masking and mental health, as well as authenticity and mental health. 'How others treat me' describes the participants past experiences, both positive and negative, of how other people have behaved towards them. Participants gave examples of these experiences directly driving, or preventing, the need to mask. They also gave examples of how these experiences indirectly drove masking through their impact on their 'self-image' and 'internal experiences' such as anxiety. Participants also described how the 'Immediate environmental context' were triggers for masking, often through the 'internal experiences' of anxiety or sensory overload. Finally, participants described the 'mental health consequences' of their experiences of masking and authenticity. Additional extracts from the interviews, not included below, can be found in Appendix G.

Table 1. List of themes and subthemes

Theme	Subtheme
1. What is masking?	
2. Authenticity	
3. How others treat me	3.1. Responses to social differences
	3.2. Bullying, ostracism and victimisation
4. Self-Image	
5. Immediate environmental context	5.1. Familiarity of context
	5.2. Characteristics of people
	5.3. Specific and physical environments
	5.4. Broader social environmental context
6. Internal Experience	6.1. Anxiety and worry
	6.2. Depression and low mood
	6.3. Sensory and cognitive overload
7. Mental Health related consequences	7.1. Anxiety
	7.2. Mood
	7.3. Self-Image
	7.4. Connection
	7.5. Exhaustion
	7.6. Sensory and cognitive overload
	7.7. Suicidality
	7.8. Protection from bullying and ostracism

Theme 1: What is masking?

Participants were diverse in how they described masking, their examples given, and the intensity of their experience. Descriptions of masking were varied both between participants and within each participant's experiences.

A small minority of participants identified just a few examples of conscious self-suppression, for instance holding in 'unrelated' or 'inappropriate' thoughts, stopping habits that annoy others or "times I have to mildly rein it in" (Participant 3). The majority of participants gave detailed accounts of masking in various ways and across various contexts. Thirteen participants gave examples of hiding or suppressing parts of themselves or their experience, particularly aspects seen as 'different' or related to being autistic. For instance, participants described suppressing and hiding emotions, sensations, stims, reactions, opinions, or interests. Sixteen participants described 'putting on an act' in order to appear more 'normal', for instance forcing

themselves to make eye contact, having a character or persona, monitoring and adjusting voice and mannerisms, and rehearsing what to say.

However, for many of these interviewees it appeared that strategies were the surface level presentation of a much deeper, and at least partially subconscious, experience. Participants described how masking was often 'not particularly tangible' (Participant 10) as it had been part of their experience of and interactions with the world for as long as they could remember. Masking was not limited to suppressing one's autistic self; it involved the suppression of a whole range of sensory and emotional reactions.

"I mean, every single time something distressing is told to me, I'm like, I do masking. I'm like, I need to try to hold this reaction back... but this is easier said than done." (Participant 18)

For several of the young people who described experiences of bullying, disparagement and ostracism, they found it difficult and anxiety provoking, to discuss masking. Although, it was not discussed directly in the interviews, there was a strong sense that past experiences had been so distressing, and potentially traumatic, that masking was a conditioned response driven by need and safety. It was therefore difficult to reflect upon masking or unmasking, due to high levels of shame relating to unmasking or 'being myself'.

"They seem trusting but then when you talk to them they're like 'you should have kept that inside your head'. They don't understand you in general. They have opinions about you going to college. I just want to live my life as a normal girl. I want to go to college. I fucking hate talking about my autism. Everyday just feels like a battle and I just wish autism could be taken off my records already… I thought

if it got taken off my record then I wouldn't have to talk about it again. That's what's hard… that I just want to live my life as a normal person… I wish there was a cure." (Participant 11)

Theme 2: Authenticity.

All participants described experiences of feeling or knowing that they were not masking, and instead feeling able to be themselves. One participant did not describe any experiences of masking and several other participants felt that overall, they did not relate to a sense of ', 'masking' or 'putting on an act'. One participant explained:

"I don't need to. I just act how I act…Really, I don't really hide it. I mean, I don't even know what the symptoms are, I can't remember the symptoms of autism but I don't really care now." (Participant 2)

Participants who related more strongly to the idea of masking were also all able to identify at least one context when "I don't have to act" (Participant 7).

'Authenticity' as a term was not used by participants, however it was conceptualised post-hoc to encompass the range of descriptions participants gave of times they were not masking. Participants conceptualised these experiences in various ways including: "I'm totally myself" (Participant 8), "I'm putting on less of an act" (Participant 10), "I can just have a good time and be myself… I don't have to pretend to be someone else" (Participant 12), and "I kind of become more of myself" (Participant 15)". Participants gave specific examples of not needing to mask, and feeling authentic or most 'myself':

"Have actually interesting conversations with people as opposed to just sticking to football… [or] something that I think the other person might enjoy." (Participant 1)

"With text, with writing, I don't have to spend all that energy on my facial expressions, so I can just put it into writing. And that can actually make it easier to talk about some more difficult conversations like mental health" (Participant 10)

"I kind of become more of myself…I can make a joke or that and that, or start talking about something I like." (Participant 15)

One participant also expressed some difficulty in knowing what authenticity or 'being myself' would feel like.

Theme 3: How others treat me.

Many participants described how masking developed as a response to other people's behaviour towards them, including how others have responded to their social differences. Participants described how experiences of other people valuing, supporting and accepting their social differences reduced or prevented the need to mask in certain contexts.

In some instances, participants made direct links between the influence of past social experience on the development of masking or authenticity.

"Because I'd spent so much of my life not fitting in and being ostracised. I thought that [masking] was the only way to be liked." (Participant 17)

"They weren't like the popular group. So they kind of, they were more accepting so I could be myself." (Participant 20)

In other examples, social experiences were described as indirectly influencing the development of masking or authenticity via their emotional impact, for instance on mood, anxiety or self-image.

"I remember when I was in like year seven, I used to get like bullied a lot. I was pretty nervous when I first joined [Saturday club] I was worried in case like people would make fun of my autism. I didn't even tell anyone I had autism… I never told anyone about my autism there". (Participant 15)

"I couldn't quite be my, fully myself around everyone [but now] I'm totally myself. People say at my new school how positive I am and it's nice to be around. Whereas at my old school it's always oh I'm so moody and all miserable. So it's nice to get that recognition that I'm being positive cos I don't realise it. It's just because people are lovely, I'm just at home. I think it's just they're more caring". (Participant 8)

Theme 3.1: Responses to social differences. Twelve of the 20 teenagers described how masking developed as a gradual response to multiple criticisms and discouragements from others over time. Specific experiences were shared of times when teenager's social differences were criticised by important people in their lives:

"I've realised like why kids never used to like me, because my social skills weren't good enough. But now that they've got better so hopefully no one will criticise me on them because I've had teachers at school criticise me on them. And I go to a special needs school, where they should really be encouraging me… I used to be told a lot to keep things inside my head. It's been very hard for me." (Participant 11)

"People have this expectation that we have to look each other in the eyes. And if you don't, you're shady or you're lying or you're a bit dodge. So I trained myself to look here… so many times I've had teachers [say] look me in the eye when I'm talking to you, look me in the eye when I'm talking to you." (Participant 17)

When asked about past experiences that had influenced the development of masking, teenagers identified experiences of negative reactions or criticism from strangers:

"So we were sitting waiting for the silver swan [exhibition] and I'm, this was when I was very young, so I didn't know how to mask yet. So I got up and started flapping. And then a woman behind me was trying to see and said 'sit down little girl'… and then when we were walking out, we saw on the guest book there was a guest in the guest book there was a message from the woman saying, good, but that little girl should have sat down." (Participant 18)

Teenagers also identified how unhelpful narratives about autism, from individuals and from wider society, also played a role in the development of masking. Participants felt that other's misconceptions or prejudices impact the parts of themselves they are able to share with others in social situations. These misconceptions included compliments for appearing non-autistic, pity when disclosing autism, and holding prejudiced views.

"There's one person who knows, because I told her when I first found out. And she was like, the first thing she said she was like, 'Really, you don't look autistic'? And I was like, okay! Sure. So then since then I just haven't bothered explaining." (Participant 20)

When asked about specific people they were more likely to mask around, participants gave examples of times people had shown ignorance or prejudices about autism, and how these incidents increased their frustration, discomfort and anxiety in social situations more generally, and reduced ease in being themselves, particularly with strangers.

"[It's harder to be myself around] people who don't agree with the obvious facts, like the earth being round... and vaccines not causing autism. And if they did, we'd be in a far better world because it would mean people wouldn't be as dumb as them. I just don't get it. Like I swear, people who are anti-vax. Why would we fake it? Why would we make it cause autism? What's the purpose?" (Participant 6)

For one participant, their experience of being made to feel 'alien' during the autism assessment process played a role in the development of masking.

"I had spent the last 2, 3 years of my life being stared at, being assessed, being looked like a guinea pig, not poked and prodded at, but like. Everyone writing on clipboards, asking me questions, asking my mum questions as if I was this alien from outer space… And as I said, although it was a relief [to receive the diagnosis], I was just like, OK, so now I definitely know that I'm not normal. Let's try and hide that." (Participant 17)

Fifteen participants also described times when their differences were valued, accepted and supported by other people, and felt these experiences had either prevented or limited the development of masking, or created contexts where masking was not necessary. Participants gave examples of the kinds of overtly positive messages they had received from friends, family and school who valued, for instance, their honesty, non-conformity, skills, kindness, and abilities.

"A lot of people in my life do specify that it's okay to be me... [brother] is very supportive of me and he doesn't really falter in his faith in me. So like he's very confident in my own abilities and sometimes more so than I am of my own". (Participant 3)

"[School] would say, don't care, just don't change yourself. Like you don't have to act." (Participant 12)

Participants also described more subtle things other people do which communicate that their differences are accepted.

"[My friends aren't] trying to like make me keep eye contact. I really hate that… people in my friendship group know that I that I don't like keeping eye contact. And that if there's a lull in the conversation, then I might just like blurt out something." (Participant 20)

Participants also valued times when they had explicitly been included, supported in a social situation, or when someone stood up for them to someone else. These experiences helped teenagers feel more confident to honestly express what they were feeling.

Theme 3.2: Bullying, ostracism and victimisation. Seven participants described masking as a response to experiences of bullying, ostracism and victimisation. Participants spoke about experiences of bullying in mainstream school, before having to move on to another school. These experiences were described as frightening, overwhelming and having a big impact on their mental health. Participants spoke about developing a mask to protect themselves from further victimisation.

"Trying to shield myself from more stuff. Just becoming a human cactus at this point, protecting their heart inside." (Participant 7)

"I thought that [masking] was the only way to be liked… I've always been picked on because I'm autistic. Whether people knew that or they didn't it doesn't matter. It's the fact that I am different." (Participant 17)

Participants reported that through repeated bullying and ostracism, masking developed as a way to find acceptance from their peers. However, when the bullying did not stop, some participants instead took on the responsibility of educating their peers about autism.

"I noticed when I was there, a lot of the people made fun of the fact that I came from [specialist autism school] because they recognised the tie colour or the jumper. But when I was, when I walked past some girls and I was like oh… don't worry we're not as bad as you think we are. And then erm, soon we got up a conversation, and I talked about like how good autism can be and that, how it's, how it's all right and not too bad and that." (Participant 15)

One participant also shared how masking is also impacted by her fears relating to her knowledge of systemic injustices towards autistic people, for instance, the treatment of autistic people sectioned under the Mental Health Act. Suppressing emotional or sensory expressions were therefore also a way to avoid potential harmful mental health interventions.

Theme 4: Self Image

Eleven participants described feelings of shame, inferiority and low self-confidence, often stemming from the experiences described in theme one, and how these feelings and images influenced the development of masking.

Participants spoke about feeling ashamed of their past social skills, behaviour or expression of distress. For instance, participants described times when their sensory reactions to an environment, a period of high energy or hyperactivity, or strong emotional expression had caused them to feel guilty for the impact on someone close to them, or ashamed of their behaviour. A negative self-image drove and reinforced masking.

"So it, maybe the anger would come to sort of at home with family rather than at the people at school…I think it would bring everyone else down. I know it's about me, but I like. And then when I see them upset, it makes me upset. Cos I've caused it, and then I'm feeling even more low." (Participant 8)

"I don't really like talking about what they [my social skills] were like at the time because it's really embarrassing because. Because I used to board and partly why I left boarding is because the care team kept talking to me about what I used to be like. And, I kept saying, please could you stop talking about what I used to be like? I'm really ashamed of the person I used to be…Like because I'm not the idiot I was then. Like I never thought about anything' (Participant 11).

Some participants directly compared themselves to neurotypical peers, presenting themselves as inferior. Autism acceptance was also discussed; low personal autism acceptance and low perceived autism acceptance from society impacted on self-image and the development of masking. Participants indicated that their mask(s) developed as a response to the narrative that a neurotypical style of communication was superior and most desirable. Some descriptions illustrated how the negative self-image they held, from these narratives, directly drove masking.

"I'm quite awkward I suppose now in comparison to other people like sort of neurotypicals especially. They can just communicate better I suppose. They just sort of have the most natural vibe, everyone listens to them and don't sort of mess up when speaking or anything… I just really want to try hard. And since the awkwardness radiating off me so it isn't quite working as well… I gesture a bit more. And ramble on because I'm trying to keep the attention on me". (Participant 7)

On the other hand, six participants described feelings of pride and self-confidence, which were rooted in or reinforced by positive responses and messages from others. For some teenagers, they reported placing very little importance on other people's opinions of them and, for instance, did not feel impacted by peer pressure or a need to fit in. Some shared strong convictions about acceptance between autistic and non-autistic people needing to work both ways and illustrated in their descriptions how a positive self-image and a positive narrative of being autistic directly reduced or prevented the need for masking.

"I feel like if I got myself into a scenario in life where I have to completely redefine myself, just to fit the scene, I'm questioning if I want to be a part of that scene, because I feel like if I need to accept them a bit, they need to accept me a bit… it's just come from this like sense that if I have to accept neurotypicals way of thinking, then why can't they accept mine? So like, if you want me to rein it in mostly sure, that's perfectly fine. But if you want me to be a different person for like seven to eight hours of the day, then you're asking for something that I'm not in the mood to give you. In some ways autism makes me more capable than normal people" (Participant 3)

Some participants also spoke about valuing their personal strengths, which related to being autistic; teenagers expressed pride in their intelligence, specific skills or abilities, self-awareness, creativity and ability to be a good friend.

'Because I feel like autism in my case is better than being normal…I wouldn't want to be normal...I wouldn't be as smart and want to do as much learning as I am. I wouldn't have my amazing memory" (Participant 6)

Some participants experienced a conflict between valuing and wanting to be themselves, and wanting to feel comfortable, but equally wanting to fit in, connect, and be respected or admired. Teenagers reported that when they were able to unmask, or feel accepted for their authentic self, both desires felt simultaneously possible.

'I'm just a free person in the civilized world and I can lie down whenever I want. In my mind, anyway… I feel different but at the same time I feel like I want to fit in… I just want to be with others. But I don't want to change myself fundamentally" (Participant 18)

Teenagers also spoke about how receiving their autism diagnosis shifted their self-image, which impacted on their masking. By becoming aware of their social differences, they developed more self-compassion and respect and reduced masking, for instance, no longer pushed themselves to do the things they previously felt they *should* want to do.

"If I'm nervous about like going to school or something and I've learnt not to force myself to try and be in situations which I know I won't like. I used to want to be invited to parties and things but now I know that I just, it's really not for me. So that's definitely helped" (Participant 20)

Theme 5: Immediate environmental context

Eighteen participants described masking, including the sensory and emotional experience specifically explored in theme 6, as contextually driven. The nature and familiarity of the context and characteristics of the people present were triggers for masking. Sometimes the environmental context was a direct trigger for the development of masking:

"Especially in a new situation, I'm very aware of having to like pull back on it, not be myself in that sense, but yeah. It's more obvious for people when I'm when they're around me 24/7" (Participant 8).

However often the context triggered emotional and sensory experiences which in turn drove masking or authenticity.

"Like if I just have to spontaneously go out to get a haircut. It's ok when I'm doing it [masking] because I focus all of my energy on doing it. It's usually the period before that's the most worrisome. It's just looking like something's wrong with me perhaps. But it's also just feeling anxious I think, that's the problem, sometimes you can't really put a finger on it" (Participant 10).

"[With friends] the same ethereal sense of being different is less so you're less on guard so you're less managing your expressions, your voice, your actions." (Participant 10)

Participants were able to reflect on this experience but noted that masking developed slowly over a long period of time and, in the moment, it was often subconscious.

Theme 5.1: Familiarity of context. Eleven participants described unfamiliar situations as a trigger for masking, and often related this to higher levels of anxiety and lower self-confidence associated with these unknown contexts. Thirteen teenagers felt that they were able to unmask and feel more authentic in familiar situations where they were more relaxed and comfortable.

"If it's something where I'm going every day, school particularly, it gets easier. So lessons are better... I don't have to worry about that kind of stuff at school. Occasionally it comes back though usually if I'm talking about something new. If it's something rehearsed like public speaking it's actually not that bad because it's rehearsed. That's why because I've done drama before and I don't really have a problem with projection because it's a rehearsed idea" (Participant 10).

To the contrary, for other participants, masking became impossible in the most emotionally overwhelming unfamiliar contexts.

"Well, if I'm really sad I wouldn't have come in the first place. Because I can mask that it school but I can't mask that in an actual [new situation]. Because I know about school, I know what lessons I have, know the teachers I have, so I know I can pretend to be okay in those lessons. Whereas in that social group I didn't know who was going to be there so something could trigger me and I could cry" (Participant 12)

Theme 5.2: Characteristics of other people. Eighteen participants identified people who they were either more or less likely to mask in the presence of. Most commonly, participants felt most authentic in their interactions with other autistic people, people they knew well, particularly close friends and family members, people who knew they were autistic and people who they shared interests with or felt similar to. This related to feeling less anxious and more relaxed in the company of

these people. More spontaneous and less structured interactions felt easier with close friends and family. On the contrary participants reported feeling more anxious and tense, and masking most commonly with neurotypical people, strangers, and people who didn't know they were autistic. Some participants reported masking most commonly with people their own age.

"And church… there's a few kids who have an autism diagnosis. I get on so well with them… It's just this circle of complete and utter transparency and honesty, and it makes my life so much easier" (Participant 17)

"Yeah if I meet any new people I think it's safer just to mask because otherwise I would seem insane. So it's when I meet new people and when I meet people who are like, you know, the typical neurotypicals, the popular people in my school, I'm mask then" (Participants 20).

With certain people, such as close friends or family, teenagers reported that the threat was reduced, their 'felt sense' of difference was reduced, and this made it possible to be more vulnerable and authentic.

"And they will be more understanding but also it's just because I think there's also something a bit because of the same sort of ethereal sense of being different is less so you're less on guard so you're less managing your expressions, your voice, your actions" (Participant 10).

Theme 5.3: Environmental characteristics. Thirteen participants often described their masking as contextual; they noted how it was elicited by specific places or situations. Teenagers noticed that they masked more in busy public places, where their anxiety was higher, and they experienced specific fears that other people would respond negatively to them or make negative judgements.

"Mostly I feel like I need to mask it when I'm in a public place. And like when there's loads crushing people I'm like, oh, I really want to run but I can't run because I wouldn't flap because people are obviously going to stare at me and think, oh, what's that girl doing running and flapping" (Participant 18)

Some participants had noticed an increase in masking after they started in a mainstream secondary school. In addition to experiences of bullying and ostracism described in theme one, masking developed through increased anxiety and feelings of difference, in the context of large numbers of neurotypical peers and sensory overstimulation.

"I guess it was just of kind of being around everyone else, sort of going from a little school into a big school and seeing how everyone else was acting and kind of like feeling that maybe I don't do the same things. I don't walk the same way" (Participant 4).

Environments which supported participants to pursue their interests, passions or strengths also supported them to be themselves and reduced the pressures to mask.

"I'm still myself… I'm more relaxed in my environment, so it's, erm, and I'm more comfortable as well, and I feel more, it's my, my second home, if you'd like… I'm doing art stuff I love, and they've got amazing facilities. So I'm really happy and positive about all of it" (Participant 8).

Theme 5.4: Broader social environmental context. Two teenagers also alluded to ways in which being autistic intersected with other aspects of their identity in specific contexts, driving masking. Masking became more necessary in environments when other people's norms, expectations or prejudices relating to gender and class were activated.

"I remember trying to act calm or normal in a posh, rich area… so like imagine this everyday person, you know, you see them on the street. Now imagine them in a restaurant. A rich one. Just like being awkward. With the handkerchief on his lap" (Participant 2).

"Well, from, I joined my prep school in year four and I played with the boys most of the time up until about year six, because that was just more fun, they were like, the girls' conversations were just really boring. But then in year seven, they started like not hanging around with me as much, so then I had, I wanted to go and try and be popular with the girls". (Participant 20)

Theme 6. Internal Experiences

Participants described how their mental health, and broader internal emotional and sensory experiences, were involved in the development of masking. Participants described some of the thoughts, feelings, and physical sensations involved in the development of and experience of masking, often relating to negative past experiences, negative self-image and social environmental factors (explored in themes 2-4).

Theme 6.1. Anxiety and worry. Fifteen participants described how anxiety contributed to the development of masking. Teenagers named specific fears relating to coming across as rude or 'weird', or doing something 'wrong', and noticed feeling tense and nervous in these situations. Some participants also described worrying about others noticing they were anxious or upset and developing an 'emotional mask' to hide feelings of anxiety or distress.

"Yeah it's just looking like something's wrong with me perhaps. But it's also just feeling anxious I think, that's the problem, sometimes you can't really put a

finger on it. I was always analysing people's behaviours and facial expressions quite a lot, usually to determine whether I was doing something wrong myself. So I often got quite an anxiety about that and still do. I don't know it's not particularly tangible, but you're just worried people are going to notice you're feeling anxious… it can get quite intrusive". (Participant 10)

"I felt really awkward. I just sat there eating my chewing gum being like 'well i'm going to try and be cool', I have chewing gum and have my Starbucks. Try and be cool and just be like I don't care, but I do, I'm freaking out inside" (Participant 12)

Other participants described specific fears of other people making fun of them or criticising them. This was often based on past experiences from which masking had developed alongside considerable anxiety, for instance about whether masking will prevent further criticism.

'Yeah, I think she apologized, but I'm still a bit nervous now as to what she still thinks of me going to college. And I really want to know what she thinks now, if she's changed because because I've tried to work on everything and now I can have a proper conversation without being criticised for something'. (Participant 11)

Additionally, fifteen participants described feeling relaxed and comfortable in the contexts where they were less likely to mask.

"At school. I mean even when we're just sat in form at tutor time and we all have all laughs and we all feel like happy and everyone's happy, and we're all like connected and happy. Because we all know each other in the class and we all have to deal with each other in the class". (Participant 12)

Theme 6.2. Depression and low mood. Three participants spoke of the influence of depression or low mood on the development of masking. For some, masking was motivated by a desire to hide their low mood from others. Two of the

participants described how long-term experiences of bullying and ostracism, alongside the distressing, led to experiences of depression and low mood, which contributed to the development of masking. For one participant the drawn-out experience of struggling to obtain a diagnosis of autism also played a role in the development of depression then masking.

"When I was undiagnosed you feel very alone because obviously you think you're neurotypical, and everyone else thinks you're neurotypical, so they expect you to act like you're neurotypical. And I thought I was, but obviously I was not. Like, definitely was not. So I was very much ostracized by my classmates. My teachers didn't know what to do with me. My parents didn't know what to do with me. I was very much inert in my own life. [Mum] was very worried that I was clinically depressed which it turns out that I actually… I felt so relieved afterwards to know that there was a reason for why I was a little bit different. But then at the same time, I had a bit of an identity crisis. And for two years did my absolute best to hide it from my classmates (Participant 17)

Theme 6.3. Sensory and cognitive overload. Four participants described overwhelming experiences of sensory sensitivities and cognitive overload, particularly when coping with the demands of the environments described in theme three. They described how masking could be highly physically uncomfortable and an additional mental and sensory demand. Specific aspects of masking, for instance forcing oneself to make eye contact, was described as physically painful.

"I always have everything I've ever done or said, what's going on right now, everything that's going in my head, I'm thinking at the same time I'm talking to you… All this stuff is because of my brain and because of my emotions and my reactions and everything that makes my head hurt… [Masking] does add to it. I

mean, I already have a dozen things to think about, I don't need like one to two more" (Participant 18)

Six participants also described how masking could became impossible when they were sensorially overwhelmed or cognitively overloaded.

Theme 7: Mental Health related Consequences

Masking had many consequences for participants; some were direct consequences to the teenager's mental health, and some were closely related to their mental health.

Theme 7.1. Anxiety. As described above, many participants described experiencing anxiety prior to and whilst masking. Three participants also described how anxiety was maintained in the longer term through masking. Suppressing emotions, stimming, and responses to stressors were noted to maintain anxiety. Masking across multiple contexts had a cumulative effect on anxiety and its impact on the young people's lives.

"You're worried that people will think you're anxious, so you try not to be anxious, but you just get more anxious. It's a self-fulfilling prophecy in a way" (Participant 10)

Five participants also explained how in situations where they felt more able to be their authentic selves, they experienced reduced anxiety and increased confidence. Anxiety was particularly reduced through the authenticity experienced in the company of other autistic people.

"It makes me feel less anxious. It does, it increases your self-esteem. It makes you have more energy because you're not spending so much on putting on an act". (Participant 10)

Theme 7.2. Mood. Six participants also described how masking lowered their mood and made them feel sad about being unable to be themselves and being disconnected or different to others. For some this led to feelings of hopelessness about the future, particularly when masking did not prevent future occurrences of bullying and ostracism.

'[After masking] I just go into my own world really I get a bit sad I don't know why' (Participant 8)

Nine participants identified how situations where their authentic selves came through, this had a positive impact on their mood.

"It gets my spirit a bit up… randomly sing and dance... it's kind of more like a way to be sane". (Participant 2)

Theme 7.3. Self-Image. Another consequence of masking was the long-term impact on self-esteem and self-image, whereby masking reinforces feelings of difference, shame and low self-confidence. Three participants specifically noted how masking negatively impacted their self-image.

"I guess it can make me feel a bit annoyed sometimes. I can feel a bit like 'I'm not normal', 'I'm having to, I'm having to kind of watch this'. I can feel a bit annoyed afterwards... I guess I can feel a bit sad as well for the same reason" (Participant 4)

Five teenagers also found that situations where they were not masking, and others responded positively, had a positive impact on their self-image.

"When I finally told people and they were all so, so great about it. That really impacted me positively... I mean societies all like 'be yourself… but not like that'. When I was myself, and even though society would say 'not like that', everyone else

was like, 'yes, like that!', it was great... It was very it was very powerful"

(Participant 17)

Theme 7.4. Connection. Three participants described how masking increased their feelings of disconnection from other people, which negatively impacted their mental health. These participants described masking as a lonely experience. By hiding their emotions, identities and authentic selves, teenagers felt as though there was a barrier between themselves and other people.

"It's like you're very close to someone, but very far at the same time, so you can know someone's behaviours and such and you can analyse them because what they did was I was always analyzing people's behaviours and facial expressions quite a lot, usually to determine whether I was doing something wrong myself. So I often got quite an anxiety about that and still do. But at the same time, you feel like you're always on sort of a different level somewhat" (Participant 20).

Five teenagers emphasised that they felt most connected to others during times when they were not masking and felt most authentic.

"[I feel most connected] when I don't have to like, act, and we can just talk about similar things, or, we can both, like, give pets cuddles, and sort of nice stuff like that" (Participant 7).

Theme 7.5. Exhaustion. Eight participants described masking as a demanding and draining experience, which took its toll on their mental wellbeing. Teenagers described how masking took up a lot of energy, physically, mentally and emotionally.

"Going outside for something that's not rehearsed can take energy. Like if I just have to spontaneously go out to get a haircut, which I did this week, can take energy to do that" (Participant 10)

'It's so tiring, trying to constantly be on the ball' (Participant 20)

Three participants who described masking all day at school explained how the exhaustion impacted them on their return home. They described how everything 'came out' at home and how this impacted their interactions and relationships with their families, which in turn impacted on their self-image and mental health.

"It all came out. So like, all everything that built up from school it all just come out.... And that'd make it worse at home. Kinda like angry and tearful and annoyed and shouting at my brother things like that" (Participant 8).

One participant described unmasking in supportive contexts as an energising experience.

Theme 7.6. Sensory and cognitive overload. Four participants identified stimming as essential for regulating emotions and sensory sensitivities, and explained how suppressing (i.e., masking) stimming took away an essential emotional regulation tool and mental health coping mechanism.

"When you're masking, you can't be yourself… you'll be in situations in which you have to deal with it as a neurotypical person would. So if you're in a loud situation, you can't block your ears or be distressed because then people will looking at me like 'what's she doing?'… it's that that will cause a meltdown because you you're getting all of this input and you can't filter it and it's horrible". (Participant 17).

On the other hand, times when these participants were able to express themselves freely, particularly through stimming, they described an immense emotional, sensory and cognitive release.

"Everything inside my brain, just vanishes for a second, and I just feel like I'm able to just process everything and all I think about really is the running. I don't care what happens. I just want to run run run run run… it all just vanishes, it all just melts away suddenly. Because I, all I really want in life is to be free" (Participant 18).

Theme 7.7. Suicidality. One participant spoke about how the exhaustion and impact of masking took a profound toll on their mental health and how at times this led to suicidal thoughts and feelings.

"For some people, it will be easier to not exist rather than to exist. There have been countless times in my life where I have felt that and it has taken me great courage to keep on existing" (Participant 17).

Another participant reflected on times when copying and mimicking others, while masking, made it difficult to distinguish their feelings and someone else's feelings. At times, this left them very vulnerable to harm.

"I made friends with this girl called [name]. And she was not the best influence because I was trying to copy people at that time so erm, she was quite depressed and quite, quite suicidal as well, and she would like self-harm and things... Yeah, we used to say like that we were one. And, yeah, we used to do everything together, including how we felt about things. I wasn't really sure what I personally believed in anymore" (Participant 20).

Theme 7.8. Protection from bullying and ostracism. Two participants described a final consequence of masking; to some extent the mask protected teenagers from further bullying or ostracism and from the severe emotional consequences of those experiences. Participants commented on the profound negative impact that bullying and ostracism had on their mental health and when masking helped them to avoid this, they experienced some relief and satisfaction.

''I'd come from such a bad place so to be in a place where I was accepted. And a place where I was liked even was just so good that it didn't matter to me that I was masking, that I was doing it falsely" (Participant 17)

"And I feel really satisfied when I'm going home because I'm like, wow, I impressed them today and they didn't find me weird, like" (Participant 19)

Discussion

The present study sought to understand autistic teenager's experiences of masking as well as the relationship between masking and their mental health experiences. The findings give a broader conceptualisation of masking than currently exists in the literature. Most participants described experiences of both masking and, conversely, of authenticity; two pathways were identified highlighting the different factors driving the development and consequences of each. Results are supportive of a bi-directional relationship between mental health and masking. Autistic teenagers' negative past experiences of other people's behaviour and reactions to them, their own negative self-image and various environmental factors contributed to high levels of anxiety in social situations. Past experiences, environmental context and teenager's emotional and sensory experiences drove the development of masking. Experiences of masking and authenticity had further consequences for mental health,

including for anxiety and mood, and related factors including self-image, connectedness, energy levels and sensory experiences.

Although various definitions have been proposed (Hull et al., 2017; Lai et al., 2017; Livingston, Shah, & Happé, 2019), within the literature the conceptualisation of masking is in its infancy (Livingston, Shah, & Happé, 2019). To date, masking has been mostly limited in definition to conscious behavioural or cognitive strategies. The current findings point towards a broader understanding of masking as something multifaceted, emotionally and psychologically rooted, which develops partially subconsciously within a social-environmental context. Participants described masking less as a choice or decision, but more as an anxiety-driven response to other's behaviour and attitudes towards them, or to uncomfortable and inhospitable environments. This fits with some previous findings that masking involves subconscious components (Bargiela, Steward, & Mandy, 2016). Participants did not limit their descriptions to social strategies or the camouflaging of autistic traits; masking included the suppression of emotion, reactions, sensory sensitivities, opinions and other aspects of identity.

Participants' descriptions of anxiety as a driver of masking is in line with previous qualitative research into masking. Hull et al., (2017) found motivations for masking included high anxiety in relation to staying safe, 'assimilating', and finding social acceptance. The current study also replicated previous findings that autistic people mask their anxiety, and other emotional reactions, in social situations, due to fears of the consequences of sharing their true feelings (Tierney, Burns, & Kilbey, 2016).

The interviews highlighted that negative past experiences of how other people behave towards autistic teenagers impacts upon the development of both masking and mental health. Previous research has highlighted the negative impact of bullying and victimisation on autistic young people's mental health (Griffiths, Allison, Kenny, Holt, Smith, & Baron-Cohen, 2019). Avoiding repeated bullying, ostracism, rejection and retaliation from others have previously been identified as external factors driving masking (Bargiela, Steward, & Mandy, 2016; Hull et al., 2017; Cage & Troxell-Whitman, 2019; Livingston, Shah, & Happé, 2019). The current interviews also emphasised the range of behaviours and reactions from others, including bullying, ostracism, alienation, rejection, criticism, and ignorance, which can contribute to the development of masking both directly, and indirectly through their impact on mental health, particularly anxiety.

The current research also showed how when autistic teenagers receive the social message, from family, peers, school, and wider society, that they are 'deficient' socially, this influences their self-image and self-esteem, and this also drives the development of masking. These findings fit with Milton's (2012) 'double empathy problem' which states that autistic and neurotypical people may both experience difficulties in understanding one another's sociality due to differences in neurology, however 'deficit-based' narratives of autism causes the duty to understand and adapt to the differences to fall on autistic people. The interviews in this study, show how autistic teenagers can internalise the 'deficit' narrative and this can lead to the development of masking in order to shoulder the burden of double empathy problems in social situations.

Mandy (2019) suggested that an environment that is inhospitable towards autistic people, could be another factor involved in the relationship between masking

and mental health. Participants in this study identified environmental factors that drove masking, both directly and indirectly through the anxiety and sensory distress caused. Previous research has captured autistic people's sense of themselves as a social minority in the company of neurotypical friends and family and how this drove the need to conform to neurotypical expectations (Crompton, Hallett, Ropar, Flynn, & Fletcher-Watson, 2020). Getting by in a 'neurotypical world' has been identified in previous research as a cause of masking (Cage & Troxell-Whitman, 2019). Current findings support this; participants reported that they masked the most in environments where social norms were most strongly held and enforced (i.e. mainstream secondary schools), they were therefore most expected to 'act neurotypical' and they were most likely to experience anxiety and sensory distress. This was especially the case in the company of neurotypical people and in environments 'built' for neurotypicals which were particularly sensorially overwhelming or unpredictable. This would fit with the social model of disability (Shakespeare, 2006), whereby the environment excludes and impairs the individual.

Participants' descriptions of the mental health related consequences of masking support a number of existing findings in the literature. Anxiety was involved in each stage of the process of masking; it was identified as a trigger, a description of the emotional experience of masking and a consequence. An association between masking and anxiety had been established in previous work (Cage & Troxwell Whitman; 2019; Hull et al., 2019; Livingston, Colvert, Social Relationships Study Team, Bolton, & Happé, 2019) and qualitative studies had identified the pressure of 'successful' masking was highly anxiety provoking (Hull et al., 2017; Livingston, Shah and Happe, 2019). Participants in the current study described how the masking of emotions, sensory distress and stimming reinforced

anxiety. Exhaustion was another mental health related consequence of masking frequently cited by participants in the current and previous work (Hull et al., 2017; Tierney, Burns, & Kilbey, 2016; Bargiela, Steward, & Mandy, 2016; Livingstone, Shah, & Happé, 2019; Cage, Di Monaco, & Newell, 2018). In line with this, autistic burnout, characterised as chronic exhaustion, loss of skills, and reduced tolerance to stimulus, is reported to stem from an inability to obtain relief from the pressures, expectations and stress associated with masking (Raymaker et al., 2020). Other consequences of masking replicate findings from previous research including low mood and depression (Cage, Di Monaco, & Newell, 2018), disconnection from others (Hull et al., 2017; Livingston, Shah and Happé, 2019) and suicidality (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018).

Cage, Di Monaco, and Newell (2018) suggested that masking may mediate the relationship between negative behaviour from others such as bullying and low autism acceptance, and consequent anxiety and depression. The current interviews indicate that bullying and low autism acceptance impact anxiety and mood directly, but for many young people masking reinforces and worsens anxiety, low mood, exhaustion, disconnection and poor self-image.

Livingstone, Shah, & Happé (2019) suggest that the negative consequences of masking may have previously been overstated. They reported that some autistic adults find that their 'compensation' strategies are successful and key to having fulfilling life experiences and the researchers suggests that future research should seek to understand which strategies are most useful and 'how their success can be maximised'. The current study does not support these conclusions. 'Successful' masking cannot be deemed so without considering the negative, and in some cases traumatic life events, which are driving an individual to mask or the longer-term

consequences for mental health, self-image and identity. Encouraging the suppression of the self and enactment of 'social normalcy' reinforces disabling and disempowering 'deficit-based' narratives of autism messages which young people internalise about themselves. Thomas (2020) compares neurodivergent masking to the Finding Nemo character Dory's strategy to 'just keep swimming' and concludes that, 'No amount of swimming… [is] enough if the world will not also adjust to meet you'.

The current research also explored the relationship between authenticity and mental health and found that experiences of being accepted, supported and valued drove authenticity, a positive self-image and a range of positive mental health consequences. Indeed, existing research suggests that authenticity is positively associated with higher self-esteem and life satisfaction (Goldman & Kernis, 2002). Authenticity is also reported as key for recovery from autistic burnout (Raymaker et al., 2020). In the current study, many participants were able to be their most authentic self in the company of other autistic people, and found these interactions and friendships particularly energising, positive and connecting. This replicates existing research findings that autistic people feel best understood, and a sense of belonging, with other autistic people (Crompton, Hallett, Ropar, Flynn, & Fletcher-Watson, 2020).

It is also interesting to consider the present findings in relation to research into autistic people's self-knowledge and theory of own mind. Autistic people may introspect in different ways to neurotypical people; some findings suggest that autistic young people find it more difficult than their neurotypical peers to recall autobiographical examples relating to knowledge of one's own personality traits (Robinson, Howlin, & Russell, 2017). In line with this, several participants in the

current study noted difficulties in reflecting upon times when they were masking as opposed to 'being myself'. This raises important questions about the qualitative nature and experience of authenticity, as opposed to masking, for autistic people. Introspection differences, and alexithymia, may be important factors in understanding how masking might develop subconsciously.

Limitations

The present study has several limitations. Firstly, qualitative research is limited in its capacity to address issues of causality. The pathways presented above, depicting the relationship between masking and mental health, and in contrast between authenticity and mental health, are not generalisable to a wider population of autistic young people at this stage. However, as was the aim of this study, the findings have generated a broader understanding of some of the factors likely to be involved in the relationship between autistic teenager's experiences of masking and mental health, which can be investigated further in future research.

Secondly, while the sample was diverse in some respects (equal numbers of teenagers identifying as male and female, geographical spread of participants, high variance in scores on quantitative mental health and camouflaging measures), in other ways it was not. There was minimal diversity in the sample in terms of race and gender identity, which limits the breadth of perspectives gathered in this study. In addition, many other aspects of identity including sexual orientation, class, religion or culture were not asked about. These limitations mean that perspectives on how neurotype and other aspects of might intersect, and specifically how being autistic and from another minoritised or marginalised community might impact experiences and consequences of masking, were missed.

A third limitation is the reliance on verbal qualitative data to understand something that is sometimes intangible, still developing and not fully conscious. It is possible that some teenagers may have limited conscious awareness of masking and its consequences. Additionally, many autistic people experience alexithymia, a difficulty identifying and describing feelings (Milosavlijevic et al., 2016). Many participants in the present study articulated their emotional experienced in great detail, but others found this more difficult, and therefore the experiences of each young person may not have been richly captured. Giving participants the opportunity to write or draw responses to questions may have overcome this limitation.

Research and Clinical implications

The current study describes the relationship between masking and mental health in autistic teenagers, highlighting the role the behaviour and reactions of others, social-environmental factors and self-image.

Firstly, future research should investigate the development and consequences of masking for young people who hold multiple marginalised group memberships i.e. they are neurodivergent and from a Black, Asian or other minority ethnic background. It will be important to investigate how other forms of discrimination, such as racism or transphobia, impact the development of masking.

Secondly, current research strongly indicates that authentic self-expression and presentation has multiple positive mental health consequences for autistic teenagers. Future research is needed to develop and test therapeutic interventions, at an individual, family and system level, to support autistic adolescents to develop a positive identity and self-image as an autistic person.

Thirdly, one of most frequently given consequences of masking, in the current and previous research, is exhaustion and burnout. Research has begun to better define burnout (Raymaker et al., 2020) and the next steps should be to empirically test the relationship between masking, burnout and long term physical and mental health consequences. Research should also aim to develop and test interventions to prevent and support autistic people experiencing burnout.

Fourthly, definitions of masking in the literature need to be expanded to focus more on how autistic people themselves conceptualise the experience, as a wholistic experience, rather than a set of cognitive or behavioural strategies.

Finally, further clinical research is needed to understand the short- and long-term impact of behavioural interventions, such as Positive Behavioural Support (PBS), on both masking and mental health. For instance, an evaluation of the use of PBS is needed to understand if and how behavioural intervention might be reinforcing masking and suppressing authentic expression or emotional regulation (e.g. stimming).

Findings from this research also have several clinical implications. Firstly, therapeutic support for autistic young people experiencing mental health difficulties must consider their access to environments which are likely to support and drive their authentic expression and interaction; for instance time with other autistic people, contexts which will nurture, value and support the young person's skills and interests, and environments which can meet young people's sensory needs and encourage sensory expression.

Secondly, therapeutic support should consider supporting young people to explore dropping masking and discovering authenticity in safe contexts.

Considerations of intersectionality here are important; particularly in contexts where authentic expression may pose risks to safety for young people who face racist or transphobic, discrimination or abuse. Mindfulness is one strategy which could empower autistic young people to become more aware of their internal experiences which drive both masking and authenticity, which could slowly enable them to step back and make more conscious decisions (Stark, 2020). However, it is essential that clinical interventions do not place all the responsibility on autistic young people to develop skills to 'stop masking'. The difficult, and sometimes traumatic experiences, plus negative social narratives which drive masking cannot be ignored in any therapeutic intervention. A whole system approach should be taken whereby external social or environmental factors, such as bullying, which are driving or reinforcing masking and mental health difficulties, should be addressed. Autistic people must be supported to understand how and why masking has developed. Narrative therapy (White, White, Wijaya, & Epston, 1990) techniques may be helpful in unpicking the 'dominant narratives' which are impacting self-image and closing down possibilities for authenticity and finding 'subjugated stories' of strength and values which can open up possibilities for dropping the mask. Autistic people are also more likely to have experienced traumatic life events (Berg, Shiu, Acharya, Stolbach, & Msall, 2016). Therapeutic work must therefore fully assess the possibility that masking is a response to trauma and if this is the case, the intervention should be trauma focused, rather than simply encouraging someone to 'drop' a traumatic stress response.

Thirdly, the long-term consequences of social skills training interventions for autistic young people need to be considered and interventions which encourage autistic young people towards masking and away from authenticity should be discontinued. Research has suggested that social skills training programmes do not

achieve their aim of improving wellbeing by teaching young people the skills to form

meaningful friendships (e.g. Gates, Kang, & Lerner, 2017). It has been suggested

that this is because the groups inhibit young people's authenticity and increase

autism stigma (Bottema-Beutel, Park, & Kim, 2018). The current research supports

the discontinuation of social skills groups and the development of groups to support

autistic young people to develop positive and authentic autistic identity.

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Part III: Critical Appraisal

Introduction

This chapter will present a critical reflection on the process of completing the research project in Chapter Two. Consideration will be given to the process of co-production and working alongside an expert by experience. Personal reflexivity will be used to explore the impact of the researcher's perspectives and positions on the research, as well as the impact of the research on the researcher. Reflections are considered in relation to broader theoretical perspectives. Further clinical and future research implications are presented with a particular focus on system-level change.

Reflection on co-production process

A key area of learning for me, throughout this project, was about the importance of co-produced autism research, which is of value to the autistic community. There were three lessons, in particular, that I learnt from working alongside autistic advocate and consultant KR. Firstly, our collaboration helped to ensure the research would be of value to the autistic community. There is a history of autism research being 'done to' the autistic community with little consideration for the quality of life of autistic people. A huge amount of autism research funding is still channelled into genetic and biological research; in 2016 44% of autism research funding in the UK was used for animal research whereas only 27% of funding was spent on the research priorities of the autistic community (Warner, Cooper, & Cusack, 2019). Autism researchers perceive themselves to be engaged with autistic communities, however autistic communities do not experience this as so (Pellicano, Dinsmore, & Charman, 2014). KR's extensive expertise in autistic people's experiences of masking guided the process of this research from study design

through to analysis and write-up. Regular discussions where we shared ideas and experiences continually shaped my thinking and approach.

Secondly, working closely alongside KR, who has led international social media conversations reaching thousands of autistic people, helped me to understand, on a deeper level, the broader social and environmental factors which drive masking for autistic people. This helped me to form interview questions that would help to capture some of these factors, rather than being solely driven by a narrower understanding of masking described in existing research.

Finally, regularly meeting with KR helped me to understand some of the current problems with autism research, which impacts the autistic community. This became extremely clear for me in the process of writing the conceptual introduction which highlighted the deficit-based, and often dehumanising, language used to describe autistic people in many research papers. This shaped my intention and determination to describe experiences of masking from the perspective of autistic people, rather than from the perspective of neurotypical people, and to use language preferred by autistic people and that supports a paradigm shift away from pathologising neurological differences (Botha, Hanlon, & Williams, 2020).

Personal Reflexivity

Reflexivity is an essential part of qualitative research; it involves exploring the impact that one's position as the researcher has on each stage of the research process (Finlay & Gough, 2008). It also involves reflection on the impact of the research on the researcher. The aim of reflexivity is partly to bring the researchers' assumptions into their conscious awareness in order to remain open to other

perspectives and findings (Starks & Trinidad, 2007), but also to use one's own perspective as a source on insight. As Finlay (2002a, p. 531) puts it 'subjectivity in research is transformed from a problem to an opportunity'.

In this section, I will reflect upon my own perspectives, experiences and positions which are likely to have shaped this research. These reflections are based on notes I took throughout the research and conversations I had with my peers, supervisor and the study's expert by experience.

My previous personal and professional relationships influenced my initial interest in this research project and some of the assumptions I brought to the research. As a teenager, I witnessed a close friend's exhausting experiences of, what we now understand as, masking while she struggled to get an autism diagnosis throughout her adolescence. In contrast, during my undergraduate degree, I worked closely with a family who hugely committed to a strengths-based narrative of autism and I witnessed the hugely positive impact this had on the autistic young person's quality of life and ability to be his authentic self. I reflected on these experiences and how they had contributed to my perspective that masking, particularly self-suppression, would have a negative impact on mental health and that authenticity would have a positive impact. I considered how I could 'bracket' (Fischer, 2009) these assumptions and remain open to diversity of experiences. I prepared for interviews by considering how to maintain a 'curious stance', and how when hearing something I thought I 'knew', making sure to clarify the meaning of certain words, ideas or experiences for that young person.

As a trainee psychologist, I have been particularly drawn towards psychosocial understandings of mental health difficulties and distress (e.g. Turner &

Lloyd, 1995; Lynch, Kaplan, & Shema, 1997; Williams & Mohammed, 2019) and I most value approaches which locate problems within systems and relational patterns rather than within individuals, for instance, narrative therapy and broader systemic approaches (White, White, Wijaya, & Epston, 1990; Jones & Haydon-Laurelut, 2019). I therefore approached this project with an assumption that the interaction between masking and mental health would at least partially be driven by social and environmental factors, which could include the role of health care systems.

Finlay & Gough (2008, p. 8) identity how personal reflexivity and introspection can offer a 'springboard for interpretations and more general insights'. I therefore included questions in my research schedule enquiring about the teenager's experiences of other people's reactions and behaviour towards them, as well as wider social messages and narratives about autism.

Very early on in the project, I spent time reading autistic people's accounts and experiences of current systems and services, as well as autistic people's views on how much of the work produced by non-autistic autism researchers or 'experts' did not possess any value for autistic people. I read more about the neurodiversity movement and found that this strongly resonated with my values and views. I hypothesised that the relationship between masking and mental health was likely driven, at least partially, by deficit-based narratives of autism driven by current services and research and policies.

In light of this, I felt very aware during this project of my position and power as a non-autistic autism researcher. Holding in mind some of the experiences I had read about, and discussed with the project's expert by experience, I feared that participants would experience me as an academic, who was intrigued by autism but

who did not truly care about improving the lives of autistic people. This certainly impacted my stance during the interviews whereby I explicitly positioned the young person as the expert who I was keen to learn from, with the long-term goal of improving mental health services for autistic people. I took time prior to the interviews to build rapport with the young person and family, and carefully set up where and how the young person would prefer to be interviewed. I spent time at the beginning of the interviews discussing the young person's interests and included questions throughout the interview about the young person's strengths and resilience. There was a moment early on in one interview where a participant assumed I was asking about masking because I thought it was something autistic teenager's 'should' be doing. In this moment, the power of my assumed viewpoint and the potential negative impact of this on the young person felt too great to maintain a 'neutral stance' and I shared some of my true hypotheses about some of the causes and consequences of masking.

The interviews had a profound emotional impact on me. When the teenagers were particularly self-critical about their 'social skills' and expressing feelings of shame about their 'un-masked' behaviour, I felt particularly anxious and sometimes guilty. I noticed that I sometimes experienced myself as oppressive or demeaning by asking these questions about the teenager's social experiences. This research was not psychodynamically informed or supervised, however I reflected afterwards about transference and countertransference in the interviews (Holmes, 2014; Knight, 2019). What was I learning about autistic teenager's experience of 'the non-autistic other' in social encounters and their experience of 'the neurotypical world' in general? I thought more about my personal context and what else was driving those feelings of anxiety and guilt.

As a clinician-researcher, when participants were expressing anxiety, shame, and sadness, it felt particularly hard to stay in the role of a researcher, rather than a clinician who could offer therapeutic help or support. I felt angry that deficit-based narratives held by powerful institutions had been internalised by many of the young people. I felt extremely sad when young people described being bullied and ostracised by their peers, and I experienced a heaviness when hearing about the responsibility these young people were shouldering to try to keep themselves physically and psychologically safe. Other times I felt completely in awe of the young people I was talking to, amazed by their strengths and resilience. When I heard stories about young people who had been told by systems, friends and families that they were accepted and valued for themselves, I felt glimmers of hope about the ways things could be different.

I carried out most of the interviews for this project while on placement in a CAMHS service and the research impacted the position I took within the team. I noticed feeling increasingly frustrated by the way that autistic young people were spoken about in the team, the way that autism assessments were conducted, and the use of social skills groups as the primary intervention. I increasingly took on the role of opening up conversations within the multidisciplinary team and introducing new perspectives by 'chipping in' during meetings and using both formal and informal consultations (Christofides, Johnstone, & Musa, 2012; Anderson, Fredman, & Stott, 2010).

Some of my reactions through this process have been reflected in wider conversations highlighting how the language used, and the paradigms that are legitimised, by powerful systems and voices, have real life consequences for the safety, stigmatisation and dehumanisation of autistic people (Botha, Hanlon, &

Williams, 2020). Calls for meaningful participatory research methods and for autistic expertise to be valued (e.g. Fletcher-Watson et al., 2019; Milton, 2014) strongly resonated with me while working on this project.

Theoretical Considerations

Existing theories have been helpful in making sense of findings that social oppression drives the relationship between masking and mental health; three areas of theoretical consideration are outlined in this section.

Firstly, 'double consciousness' is a useful concept to apply to autistic masking. Double consciousness was first written about by Du Bois in 1897 to describe Black American's experience of "always looking at oneself through the eyes" of a racist society and how societal contempt impacted individual and collective self-worth. We can apply this concept to autistic peoples' experience of evaluating themselves using neuro-normative standards in a world which defines neurological and social differences as disorder. Masking maps on to this sense of evaluating oneself through the eyes of an oppressive other. This fits with participants self-criticism in relation to not meeting neuro-normative standards, reinforced by bullying and victimisation, and driving masking in order to hide social differences from neurotypical others.

Secondly, it is important to consider the role dominant theories of autism in driving pathologising narratives of autism (Murray 2019). Not only do dominant theories, including the theory of mind deficit hypothesis (Baron-Cohen, Tager-Flusberg & Cohen, 2000), central coherence theory (Happé, 1999; Roth, Barson, Hoekstra, Pasco, & Whatson, 2010) and extreme male brain theory (Baron-Cohen, 2002), leave much of autistic experience unexplained, they also perpetuate harmful

misconceptions. Monotropism (Murray, Lesser & Lawson, 2005; Murray, 2019), a much less well-known theoretical account of autism, offers a non-pathologising explanation of autistic cognition and experiences. 'Monotropic brains' focus on singular, or fewer, interests at any one time, attracting more processing resources to a singular interest, leading to strengths in hyper-focusing and difficulties with 'deal[ing] with things outside of our current attention tunnel' (Murray, 2019). This is compared to the polytropic brains of non-autistic people, which have multiple interests aroused at one time and attention is spread more widely and thinly. The premise of an intense 'single attention' is used to explain autistic people's discomfort with interruptions and changes to plans or routines, sensory processing differences, social differences and focused interests.

When one applies monotropism to autistic people's experiences of masking, it is easy to see why conceptualising masking as a 'choice' or 'decision' is not useful. The intensity with which an autistic mind may hyper-focus on masking could be a reflection monotropism, particularly in the social and environmental safety driven context described above, rather than a reasoned 'decision' or 'choice'. This fits with participants descriptions of the mental and sensory intensity of masking. It is possible that, to date, autistic people's self-awareness regarding masking has mistakenly been understood as implying 'choice'. I feel particularly concerned about the ethics of conceptualising masking is a 'choice' when it is driven by social oppression.

Thirdly, the minority stress model, is also useful in making sense of the relationship between masking and mental health. Minority stress theory describes how members of a stigmatised minority groups experience poorer mental and physical health outcomes due to exposure to increased stressors (Pascoe and Richman, 2009). In the current study, participants described how others responses to

their differences impacts their self-image, mental health and drives masking. This fits with research which has shown that autistic adults' who experience more minority stressors, including masking, discrimination and internalised stigma, also experience poorer mental health (Botha & Frost, 2018). The theme 'immediate environmental context', also demonstrated how masking and anxiety were both often contextual to situations where teenager's minority status was most activated, for instance with neurotypical others.

Implications for future research and clinical practice

The impact of the deficit-based and pathologising narratives of autism in driving autistic people's experience of both masking and mental health difficulties has a number of implications for future research and for clinical practice.

Future research should investigate the impact of deficit-based narratives of autism held and perpetuated within specific systems. This is especially important in diagnostic services where long-term outcomes of the information given should be investigated. Practice-based evidence should include following up with young people who are given an autism diagnosis and their families to hear about their experience of the assessment process and the impact of the information given. Participatory research is needed for autistic people, researchers and clinicians to co-design pre-assessment and post-assessment information resources which are non-deficit based and focus on the neurodiversity paradigm, non-pathologising accounts of autism and co-occurring conditions. These resources should aim to support young people to develop a positive autistic or neurodivergent self-image. Research should investigate the impact of these resources compared to traditional ones.

Work to develop such resources has already begun, and autistic advocates have taken a leading role in developing and signposting families to safe autism-positive, autistic-led support groups (Rose, 2017). Increasingly books and other resources, written about autism by autistic people, are being published (for instance, Dalmayne, 2016; Heaver et al., 2017; Purkis & Goodall, 2018). Parenting programmes are also being developed to combat and protect against autism stigma (Lodder, Papadopoulos, & Randhawa, 2020). Additionally, it is essential that diagnostic services are using autism positive resources, developed by autistic people, for staff training and professional development, as well as signposting them to children and families.

Research should also investigate the impact of deficit-based narratives of autism within universities and research groups. Nationwide audits are required to understand what psychology students are taught about autism. Research studies should also evaluate the impact of autism teaching and training led by autistic trainers compared to that led by neurotypical trainers. Research is also needed to explore the impact on autistic people of published research papers which use pathologising language and concepts. This is particularly necessary in the current context whereby an international social media campaign is advocating for autistic people to boycott autism research due to the harm it can cause. Autistic people need to be meaningfully consulted in all autism research (Milton, 2014).

Regarding clinical implications, all professionals working with autistic young people require regular autism training and CPD sessions. These sessions should be led or co-led by autistic adults. Meaningful participation schemes should be set up in all neurodevelopmental and mental health teams working with autistic young people,

to ensure that their views and experiences are at the heart of all decision making. Autistic adults should be involved in the delivery of services for autistic young people at every level. Autistic young people need access to other autistic people of all ages in non-prescribed and autistic-led spaces. This could take the form of peer support groups but should be delivered flexibly to meet the needs of each young person. All autistic adults working for the service should be employed at the same pay bands as other clinicians in order to place equal value on experts by experience. They should also be provided with suitable support and supervision.

Neurodiversity should be understood by staff, and taught to all students, in both mainstream and specialist educational settings. Future research should investigate whether this educational intervention reduces the amount of bullying and ostracism experienced by autistic and neurodivergent young people.

To conclude, systems must listen and respond to autistic people advocating for change. In the words of a participant in the current study, "Don't treat autistic people like they're a problem, because we're not!" (Participant 17).

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Appendix A: Joint working statement

Outline of joint working

The qualitative study described in the project was one part of a wider project investigating masking in autistic teenagers.

The quantitative study (phase one) was contributed to by LH (PhD candidate), LC (DClinPsy trainee), BH (DClinPsy trainee), and AWB (DClinPsy trainee) and was supervised by WM. WM and LH conceived of the project and LH obtained ethical approval for the study. LH recruited 28 families and met with 29 families. LC recruited 21 families and met with 11 families. BH recruited 7 families and met with 14 families. AWB recruited 4 families and met with 6 families. LH completed a quantitative analysis and wrote up a PhD empirical paper entitled, 'Cognitive predictors of self-reported camouflaging in autistic adolescents'. BH completed a quantitative analysis and wrote up a DClinPsy thesis empirical paper entitled, 'The role of VIQ in the camouflaging of autistic traits'.

The qualitative study (phase two) written up for this thesis was conceived by LC. An amendment to ethical approval was obtained by LC and LH. LC recruited 20 families and conducted the 20 interviews. LC completed the qualitative analysis. LH contributed to credibility checks for the analysis. LC wrote up the current thesis.

Appendix B: Parent and teenager information sheets

Participant Information Sheet (Parent/Caregiver, recruited outside NHS)

Title of Project: Phase 2: How do social experiences impact the mental health of autistic teenagers?

Researchers: Dr William Mandy and Louise Chapman

Research Department of Clinical, Educational & Health Psychology,

University College London

WC1E 6BT

l.chapman@ucl.ac.uk   w.mandy@ucl.ac.uk

020 7679 592

Invitation to take part

Your child is invited to take part in a study looking at how social experiences impact the mental health of autistic teenagers. This is a student study being completed as part of Louise Chapman's Doctorate in Clinical Psychology (DClinPsy). The study is run by researchers from University College London (UCL) in collaboration with Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, the Whittington Hospital NHS Trust and East Kent Hospitals University Foundation Trust.

Before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Your child has been given their own copy of this information sheet; please discuss the study with them. Ask the researcher (Louise) if you have any questions or if anything is unclear. Take time to decide whether or not you and your child wish to take part.

Aims of the study

This study aims to investigate the impact of social experiences on the mental health of autistic teenagers, through a short interview.

Why have my child and I been approached?

You have received this information sheet because you and your child have already taken part in the first phase of this study "Social Skills in Autistic Teenagers". If your child has a diagnosis of autism, is aged between 13 and 19 years, and does not have a learning disability, they are eligible to take part. You told us that you did not mind be contacted about taking part in another study.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to give a reason for not taking

 part, and there will be no consequences for your child's medical treatment or your legal rights for not taking part in this study.

What will happen to me if I take part?

The study will involve your child taking part in a 30 minute interview about the social situations they encounter, how they feel, and what they do during and following these situations. The study will take place at your home, or at UCL in private testing rooms.

What will my child and I have to do?

The researcher may come to your home, or you and your child will be invited to come to testing rooms in UCL, depending on your preference, at a time that suits you. The researcher will go through this information sheet with you again, and you will be asked to sign a consent form agreeing that your child will take part. If your child is aged 13-15, you will be asked to consent on their behalf and they will complete an informed assent form. If your child is aged 16-19, they will complete their own consent form. This will take up to 15 minutes.

In the interview your child will then have a conversation with the researcher about the types of social situations they encounter, how they feel during these situations, and what they do during these situations. The researcher will also ask questions about their mental health more broadly. The researcher provide paper and pens in case your child would prefer to draw or write answer at any point during the discussion. The researcher will make it very clear to your child that they do not have to answer any questions which make them feel uncomfortable. A "stop/pause" card will be provided for your child to stop the conversation non verbally if they prefer. This conversation will be audio recorded and take up to 30 minutes.

Your child does not have to take part in any part of this study if you do not wish to. If at any point your child wishes to withdraw from or pause the study, you or they can do so by telling the researcher or experimenter that they wish to stop. They do not have to give a reason for pausing or withdrawing, and there will be no repercussions for withdrawing. If you have travelled to the study site, your travel expenses will still be reimbursed even if you withdraw during or after the testing session.

Disadvantages of taking part

There are no predicted disadvantages of taking part for you or your child. If at any point during the study you or your child become tired, distressed, or wish to take a break, you or your child can pause the study by telling the experimenter you wish to do so. They do not have to give a reason.

Benefits of taking part

The interview your child will take part in does not represent a full clinical assessment, and cannot be used as an assessment for their abilities and/or difficulties. However, once the findings are analysed and published, we hope your responses will improve the

understanding of autism researchers, clinicians, and educators, as well as the broader community, about the impact of social experiences on autistic teenagers' mental health. If you are interested, we can send you a summary of our findings when the study is completed.

Confidentiality

Your child's interview will be audio taped. The purpose of the recording is to allow us to capture all the information discussed during the interview, which is important for us to analyse later. The recording will be uploaded to a password protected file then typed up, anonymised and afterwards the recording will be deleted. The transcript of the interview will then be analysed to find key themes in what people say about their experiences.

Transcripts will be stored securely, on a secure internet server only available to the researchers involved in the study, until the completion of the study (September 2020), at which point they will be destroyed. All other data will be stored securely and any personally identifiable information will be removed. When the study finishes in September 2020, we will keep your data in an anonymous format unless you ask us to delete it.

The findings of this study may be published in academic journals and/or presented at conferences. All findings will anonymised so your child cannot be identified. Your data will be stored in accordance with the Data Protection Act 1998.

Reimbursement

No reimbursement is offered for this study. However, any travel expenses incurred while travelling to and from the study site within London will be reimbursed, provided full receipts are given to the researchers. Your travel expenses will be reimbursed for travel within London, up to £10 for adults and £5 for children (aged 13-15). You will need to email travel receipts to the researchers (l.chapman@ucl.ac.uk).

Withdrawal

Your child will be able to withdraw from this study at any point by asking the experimenter to stop the study. If your child withdraws from the study, the data you have provided so far will be retained unless you request for it to be removed from the study. You can also withdraw your child's data from the study at any point until June 2020, by contacting the researchers and asking for your data to be removed. You do not need to provide an explanation for your withdrawal, and there will be no repercussions for withdrawing.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Louise Chapman (Researcher) on l.chapman@ucl.ac.uk, who will do her best to answer your

questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, UCL complaints mechanisms are also available to you. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. Please make the claim in writing to Dr William Mandy who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This study was reviewed and approved by the University College London Research Ethics Committee and the NHS Health Research Authority (London - Bloomsbury Research Ethics Committee, REC Reference: 17/LO/2055).

Who is organising and funding the study?

This study is being funded by University College London, who are sponsoring the study.

What will happen to the results of the study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Louise Chapman's DClinPsy thesis. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

Who to contact

If you have any further questions about the study, we are happy to discuss these with you. It is important that you and your child fully understand what you are being asked to do before you begin the study. Please contact Louise Chapman (l.chapman@ucl.ac.uk) or Dr William Mandy (w.mandy@ucl.ac.uk: 020 7679 1675) for more information, or if you have any questions or concerns about this study.

If you and your child are willing to take part in this study, please contact the researchers to and confirm your interest. A testing time and location will be arranged to suit you. Agreeing to take part does not mean you have to do so; you can still withdraw at any time and do not have to give a reason for withdrawing.

Participant Information Sheet (Adolescent, 16-19)

Title of Project: Phase 2: How do social experiences impact the mental health of autistic teenagers?

Key Researchers: Dr William Mandy and Louise Chapman

Invitation to take part

You are invited to take part in a study looking at the social experiences and mental health of autistic young people. This is a student study being completed as part of Louise Chapman's Doctorate in Clinical Psychology (DClinPsy) research. The study is run by researchers from University College London (UCL) in collaboration with Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, and the Whittington Hospital NHS Trust.

Before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Your parent/caregiver has been given their own copy of this information sheet; please discuss the study with them. Ask the researcher (Louise) if you have any questions or if anything is unclear. Take time to decide whether or not you wish to take part.

Aims of the study

This study aims to investigate the impact of social experiences on the mental health of autistic teenagers, through a short interview.

Why have I been approached?

You have received this information sheet because you have already taken part in the first phase of this study "Social Skills in Autistic Teenagers". If you have a diagnosis of autism, are aged between 13 and 19 years, and do not have a learning disability, you are eligible to take part. You told us that you did not mind be contacted about taking part in another study.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to give a reason for not taking part, and there will be no consequences for your medical treatment or your legal rights for not taking part in this study.

What will I have to do?

The researcher may come to your home, or you and your parent/caregiver will be invited to come to activity rooms in UCL, whichever you prefer, at a time that suits you. The researcher will go through this information sheet with you again and you will be asked to sign a form saying that you consent to take part. Your will then have a conversation with the researcher

about social situations, and mental health. This conversation will be audio recorded.

Below is a timeline of what will happen during the study. If at any point you want to take a break, or stop the interview, just tell the researcher and they can pause or stop the study.

1.

10 minutes

1. The researcher will come to your house, or you will arrive at UCL with your parent/caregiver. The researcher will explain what the study involves again, and ask your consent to take part in the study. You will be asked to sign a piece of paper saying that you consent to take part.

2.

30 minutes (or less if you prefer)

2. Take part in a short interview. The researcher will ask you questions about your experiences in social situations e.g. the time you spend with other people. They will also ask you questions about how you feel and what you do in these social situations. They will also ask about mental health and how you feel in day to day life e.g. times you are happy, worried, stressed out or relaxed. This conversation will be audio recorded.

If there is anything you do not want to talk about, it is not a problem! You do not have to take part in any part of this study if you do not wish to. If at any point you wish to stop or pause the study, you can do so by telling the researcher that you wish to stop. There will also be a "stop/pause" card on the table you could point to instead. You do not have to give a reason for pausing or stopping, and nothing bad will happen to you because you chose to stop the study.

Disadvantages of taking part

There are no predicted disadvantages of taking part. If at any point during the study you feel tired, stressed, or want to take a break (for example to use the toilet), you can pause the study by telling the researcher you wish to do so or pointing to the 'Stop / Pause' card on the table. You do not have to give a reason for pausing the study.

Benefits of taking part

We will not be able to use your responses to tell you anything about you as an individual. However, we hope that by combining the responses of many teenagers, we can learn more about autistic teenagers' social experiences and mental health and share this information with autistic people, their families, schools, and the wider community. If you are interested in the results of the study we can send you a summary once the study is complete.

Confidentiality

Your interview will be audio taped. The purpose of the recording is to allow us to capture all the information discussed during the interview, which is important for us to analyse later. The recording will be uploaded to a password protected file then typed up, anonymised and afterwards the recording will be deleted. The transcript of the interview will then be analysed to find key themes in what people say about their experiences.

Transcripts will be stored securely, on a secure internet server only available to the researchers involved in the study, until the completion of the study (September 2020), at which point they will be destroyed. All other data will be stored securely and any personally identifiable information will be removed. When the study finishes in September 2020, we will keep your data in an anonymous format unless you ask us to delete it.

The findings of this study may be published in academic journals and/or presented at conferences. All findings will anonymised so you cannot be identified. Your data will be stored in accordance with the Data Protection Act 1998.

Reimbursement

No reimbursement is offered for this study. However, any travel expenses incurred while travelling to and from the study site will be reimbursed, provided full receipts are given to the researchers. Your travel expenses will be reimbursed for travel within London, up to £10 for adults and £5 for children (aged 13-15).

You will need to email travel receipts to the researchers (l.chapman@ucl.ac.uk).

Withdrawal

You can stop taking part in this study at any point by asking the researcher to stop. After you have finished the study, you can ask for your data to be removed at any point up until June 2020. You do not have to give a reason for stopping the study or for asking for your data to be removed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Louise Chapman (Research) on l.chapman@ucl.ac.uk, who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, UCL complaints mechanisms or National Health Service complaints mechanisms are also available to you. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr William Mandy who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This study was reviewed and approved by the University College London Research Ethics Committee and the NHS Health Research Authority (London - Bloomsbury Research Ethics Committee, REC Reference: 17/LO/2055).

Who is organising and funding the study?

Researchers at University College London are organising this study. They will not get any extra money for doing this research. The research is being paid for by University College London, who are sponsoring this study.

What will happen to the results of the study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Louise Chapman's Doctorate in Clinical Psychology (DClinPsy) research. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

What next?

Please read through this information sheet with your parent/caregiver. If you have any further questions about the study, we are happy to discuss these with you: email Louise at l.chapman@ucl.ac.uk.

Once you and your parent/caregiver are happy to take part in the study and have had all

your questions answered, we will contact your parent/caregiver to arrange a time and location for you to come and complete the study. Agreeing to take part does not mean you have to do so; you can still stop at any time and do not have to give a reason for stopping.

What to remember:

- The interview will take place in a private room. Only the researcher and your parent/caregiver (if you want them there) will be able to hear the interview.
- The interview will last 30 minutes, and you can take as many breaks as you need if you get overwhelmed or for any other reason.
- You don't have to participate if you want to. Nothing bad will happen to you if you change your mind.
- When the study is completed you can receive a summary of all the findings. No one will be able to know that you took part or what your responses were from this summary.
- Your privacy will be respected. Only the researchers and your clinicians will ever have access to your responses.
- We are very grateful to you for helping us to learn more about autistic teenagers' social experiences and mental health, so that we can help other people to understand as well.

Appendix C: Parent and teenager consent forms

CONSENT FORM: PARENT/CAREGIVER

Title of Project: Phase 2: How do social experiences impact the mental health of autistic teenagers?

Name of Researcher: Louise Chapman, Dr William Mandy

Please initial box

1. I confirm that I have read and understand the information sheet dated 06/09/2019 (version 2) for the above study. I have had the opportunity to consider the information, discuss it with my child, ask questions and have had these answered satisfactorily. ☐

2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time without giving any reason, without my child's medical care or legal rights being affected. ☐

3. I understand that data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my child's taking part in this research. I give permission for these individuals to have access to my child's records. ☐

4. I agree for myself and my child to take part in the above study. ☐

5. I consent for audio recordings of my child's responses to be made. ☐

6. I consent for researchers to access recordings of my child's responses. ☐

7. I agree for my and my child's anonymised data to be used in future research studies. (Optional) ☐

8. I agree for the researchers to store my and my child's personal data so they can contact us in the future to ask if we would like to take part in other studies (Optional) ☐

_____
Name of Teenager

| _____ | _____ | _____ |
| Name of Parent | Date | Signature |

Louise Chapman
_____
Name of Person   Date   Signature
taking consent
When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

Study Number: 17/0554
Patient Identification Number for this study:

ASSENT FORM: ASD ADOLESCENT 13-15

Title of Project: Phase 2: How do social experiences impact the mental health of autistic teenagers?

Name of Researcher: Louise Chapman

Please complete this form after you have read the Information Sheet and discussed it with your parent/caregiver. If you are unsure about any of the statements, or if you have any further questions about the study, please ask the researcher (Louise) or discuss this with your parent/caregiver before continuing.

Please initial box

1. I confirm that I have read and understand the information sheet dated Version 2 (06/09/2019) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I agree for audio recordings of my responses to be made.

4. I agree for researchers to watch and listen to recordings of my responses.

5. I understand that my responses will be stored securely and any personally identifiable information will be deleted once data have been coded.

6. I understand that data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data

7. I agree for my anonymised data to be used in future research studies. (Optional)

8. I agree for the researchers to store my personal data so they can contact me in the future to ask if I would like to take part in other studies (Optional)

9. I agree to take part in this study.

Assent form IRAS: 233394 Version 5 Dated 19/07/2019 Page 1 of 163

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking assent

_____   _____   _____
Name of Chief Investigator Date   Signature
(if different to the person taking assent)

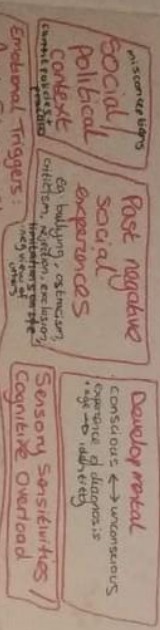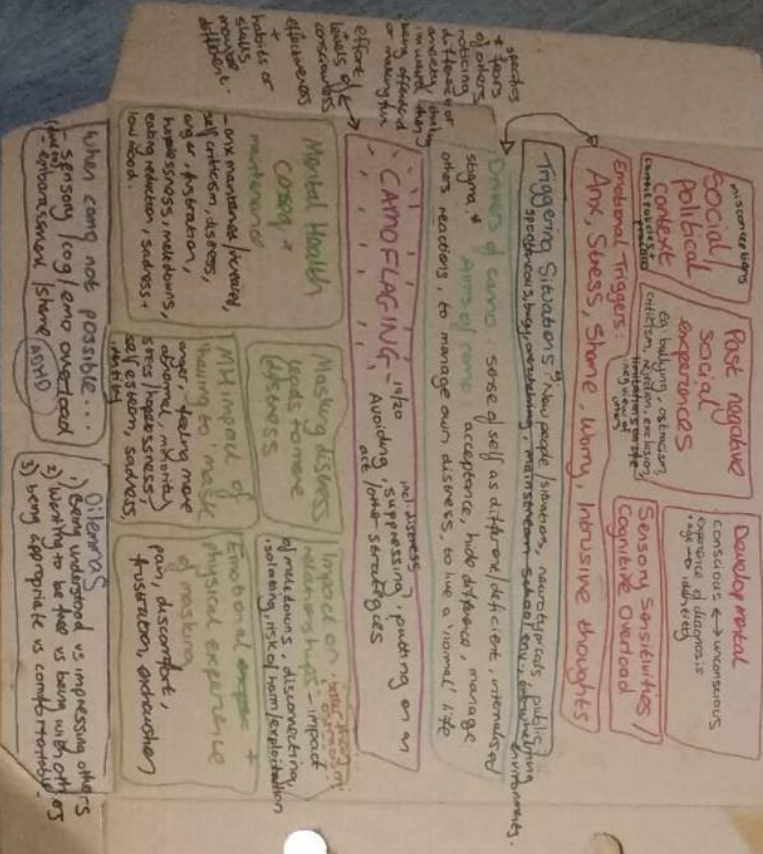When completed: 1 for participant; 1 (original) for researcher site file

Appendix D: Semi structured interview schedule

1. People prefer to talk about autism using different language / words. Do you describe yourself as an autistic teenager or a teenager with autism? Or something different? (show to options on paper)

2. What are your preferred gender pronouns? (show options on paper)

3. How do you like to spend most of your free time currently? What do you most enjoy / are you most interested in right now?

4. Can you tell me about when and where you spend time with other people? This could be times you choose to spend with other people or times you have to spend with other people. (E.g. School/home/shops etc)

5. How do you feel during social situations?
   a) Can you describe how you feel in these situations? (You could tell me in words or describe what images or sounds come to mind...)
   b) Can you describe how you feel in your body in these situations? (You could tell me in words or describe what images or sounds come to mind...)
   c) Are there other (non-social) situations which make you feel like this?

6. When you feel X, what do you do? What are the things you do to cope in these situations? What do you do to feel better?
   a. What do you do? (E.g. Activities/moving your body/going to a place etc)
   b. How does it feel when you...? What happens to your thoughts and your body when you…?
   c. Is there anything you try not to do? Are there things you don't do or avoid doing in these situations?
   d. Do you remember when you started doing this?
   e. Do you remember why you originally started doing this? How did you find out these things helped/didn't help?
   f. What happens to your thoughts and feelings afterwards? How does it compare to before?
   g. Are there any benefits / positive consequences for you of doing X?
   h. Are there any costs / negative consequences for you of doing X?
   i. Are there other things that you do to....

7. Are there situations where you have to put on an act? Is there anything you change about yourself or try to cover anything up? Do you plan or prepare things? Some autistic people have told us that they put a lot of effort into hiding being autistic or "pretending to behave more like non-autistic people"? (If necessary give examples: other people have mentioned... *pretending to make eye contact, pretending to be relaxed, prepared things to say or jokes or phrases in advance, practicing gestures or facial expressions in advance, copying others language or body language, trying to make voice sound more 'normal', pretending to be interested in an activity or topic, studying human behaviour)*
   a. Is this something you have experienced / done?

b. What do you do? Can you give some examples of things you do to act like non-Autistic people?

c. What do you try not to do? Can you give some examples of things you stop doing to act like non-Autistic people?

d. Why do you think you do it?

e. Can you think of the last time you did this? Or an example of something you do regularly?

f. *What happened when you X? [use teenagers' words]*

g. *Were there any benefits of X?*

h. *What are the costs / negative consequences of X?*

8. Are there situations where you **don't** have to do these things / **don't** feel X? Around certain people or in certain places? Does it make a difference if the person / other person are autistic or neurotypical? Are there people or places where you are able to be yourself?

9. Lots of people have times when they experience mental health difficulties. What does good mental health mean to you? What do we mean by 'mental health difficulties'?

10. Can you describe any times when you have experienced… [use teenagers words] e.g. mental health difficulties)?

11. When do you feel most like X? What can trigger / lead you feel /experience X?

12. Do you think when you X ([use teenagers words] e.g. mask /camouflage), it has an impact on ([use teenagers words] e.g. anxiety)? (E.g.1. when you try to cover up being autistic at school, how does this affect the anxiety, E.g.2. studying and copying the behaviour of the non autistic kids at school... does this have an impact on your mental health).

13. When did you get your autism diagnosis? Did this impact on masking and / or mental health?

14. What helps you to X ([use teenagers words - something they have suggested is preferred] e.g. be yourself / feel better / feel most comfortable) in social situations? What do other people do? Are there other things that help you / could help?

Appendix E: Preliminary thematic map

Social, Political Context

- misconceptions

Develop mental
- conscious ↔ unconscious
- experience of diagnosis is
- sig. to identity

Past negative social experiences
- eg. bullying, ostracism, rejection, exclusion

Emotional Triggers:
Anx, Stress, Shame, Worry, Intrusive thoughts

**Sensory Sensitivities /
Cognitive Overload**

Triggering Situations: new people/situations, neurotypicals, public settings, mainstream school, overwhelming environments.

Drivers of camo: sense of self as different, deficient, internalised stigma + aims of camo: acceptance, hide difference, manage others reactions, to manage own distress, to live a 'normal' life

CAMOFLAGING 19/20
- incl. distress
- Avoiding, suppressing, putting on an act / using strategies

Masking distress leads to more distress

Impact on:
- relationships, burnout/stress, meltdowns, dissociation, isolation, risk of harm/exploitation

Mental Health Coping → maintenance
- anx, maintained/increasing, self criticism, distress, anger, frustration, hopelessness, meltdowns, stress, hopelessness, low mood, self esteem, sadness, safety.

Emotional experience + masking
- pain, discomfort, frustration, exhaustion

Dilemmas
1) Being understood vs impressing others
2) Wanting to be true vs being with others
3) being appropriate vs comfortable/natural

When camo not possible...
- Sensory [cog]/emo overload
- embarrassment/shame (ADHD)

Positive Social experiences

- Small groups, familiar people, shared interests, groups + clubs, instruct, messaging, other autistic people, network, normal.
- Inclusion, understanding, recognition, feeling less different, feeling valued

familiar/reduced

Positive School Experiences
- environments: pos, close+
- lasting relationships with teachers, support, pos
- peer relationships

Context: specific people, environments, feel more relaxed

NEURODIVERGENT OTHERS: not necessary

Other people is school based/
- reactions, messages, acceptance, support, encouragement
- trust, compliments

ACTIVE RESISTANCE
- should have to mask, autism as strength, benefits of non conforming, neg view of mask, non accepting others, act of defiance.

NOT CAMOFLAGING — strategy
- Disclosing autism, dropping an act or view, freely being myself, unable to mask

Don't feel a pressure — who

- authenticity / acceptance
- improves self esteem
- reduced anxiety
- feeling more me
- embarrassment / shame

Appendix F: Confirmation of ethical approval

Dr William Mandy
Research Department of Clinical, Educational & Healthy
Psychology
1-19 Torrington Place
London
WC1E 7HP

21 December 2017

Dear Dr Mandy

Letter of HRA Approval

Study title:	**Social Skills in Autistic Teenagers**
IRAS project ID:	**233394**
REC reference:	**17/LO/2055**
Sponsor	**University College London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

NHS
Health Research Authority

London - Bloomsbury Research Ethics Committee

HRA RES Centre Manchester
Barlow House 3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 02071048127

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

04 December 2018

Ms Laura Hull
Department of Psychology, University College London
26 Bedford Way
London
WC1H 0AP

Dear Ms Hull

Study title:	**Social Skills in Autistic Teenagers**
REC reference:	**17/LO/2055**
Amendment number:	**Amendment 1 05/10/2018**
Amendment date:	**06 November 2018**
IRAS project ID:	**233394**

Amendment requests approval to conduct follow-up semi structured interviews and an additional quantitative measure in order to understand how autistic teenagers' camouflaging behaviours may be related to their mental health and wellbeing. Also propose to introduce lottery incentive (of gift vouchers worth £230) as additional funding now available.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Appendix G: Additional interview extracts

Theme	Subtheme	Additional interview extracts
2. How others treat me	2.1. Responses to social differences	"Staff person was saying 'oh we're dealing with it and stuff'. And best friend was just like, 'No. No, you haven't been dealing with it. It shouldn't have got to this point'. And just, you know it's serious when your best friend is absolutely stone faced... So I suppose talking stuff through with her it just sort of helps me to validate it, validate my feelings and not sort of go on a godzilla rampage for no reason." (Participant 7)
	2.2. Bullying and Ostracism	"I had enough of it and I went to my head of year saying, look, this is happening and I want to do this. And I essentially wrote a little talk where I said. Essentially, I told my story from when I was really little…. It was more from the fact that I was completely, utterly sick and tired of being talked about behind my back." (Participant 17)

""This school year I've been much much much much much more wary of jokes because jokes are what got me hurt and I suppose I'm getting me more prickly like a cactus trying to shield myself from more stuff. Just becoming a human cactus at this point, protecting their heart inside. But be careful with the rest of the world because you don't know who wants to hurt you. But pass it off as a joke. Because obviously my feelings are a joke now." (Participant 7)

"But there's still a clause in the Mental Health Act that implicates autism because it describes behaviour that happens in meltdowns, like dangerous or aggressive behaviour to themselves or other people, is like deemed psychosis … Autistic people are medicated in these mental health hospitals for problems they do not have… And that leads to them many actually developing mental health issues… if I hadn't been diagnosed [with autism] so early on I am almost certain that I'd be in one [a mental health hospital] now." (Participant 17). |
| 5. Internal Experience | 5.3. Sensory and cognitive overload | "Yeah because it's hard to hide my reaction if I'm struggling with a texture, that's not something I can really hide." (Participant 4) |

6. Mental health related consequences	6.3. Self-Image	"Yeah, definitely, because I realised that I wasn't doing it automatically, I wasn't, I was having to really work to contribute to conversations, so that made me feel like I'm just really not popular, and like 'how come everyone else can just do it, why can't I?" (Participant 20)
	6.6. Sensory and cognitive overload	"And if you're the only one who's having an [sensory] issue, you feel completely alone in it. And a lot a lot of autistic women actually develop like OCD, selective mutism, anxiety, depression, because this world is so totally inappropriately built for people like us." (Participant 17)