Extending the Minority Stress Model to Understand Mental Health Problems Experienced by

the Autistic Population

by

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## Abstract

Research into autism and mental health has traditionally associated poor mental health and autism as inevitably linked. Other possible explanations for mental health problems among autistic populations have received little attention. As evidenced by the minority disability movement, autism is increasingly being considered part of the identities of autistic people. Autistic individuals thus constitute an identity-based minority and may be exposed to excess social stress as a result of disadvantaged and stigmatized social status. This study tests the utility of the minority stress model as an explanation for the experience of mental health problems within a sample of high-functioning autistic individuals (*N*=111). Minority stressors including everyday discrimination, internalised stigma, and concealment significantly predicted poorer mental health, despite controlling for general stress exposure. These results indicate the potential utility of minority stress in explaining increased mental health problems in autistic populations. Implications for research and clinical applications are discussed.

# Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population

Over the last two decades, the meaning of the diagnosis of Asperger Syndrome (AS) and High-functioning autism (HFA) has changed, with more autistic individuals considering autism central to their identity as opposed to a disorder (Aylott 2000; Bagatell 2007; Elliman 2011). The vast majority of research into HFA/AS has tended towards researching the autism spectrum through the biomedical model, specifically its aetiology and a possible cure (Pellicano, Dinsmore, and Charman 2014) rather than recognizing HFA/AS as normal forms of variation in human psychology. Less than 1% of autism research funding in both the United States and the United Kingdom has gone into researching adults on the spectrum, nor any social factors that may contribute to the high rates of mental health problems experienced by people on the autism spectrum (Pellicano et al. 2014). Increasingly autistic people themselves are beginning to consider AS and HFA a form of neurodiversity, and a key part of their identity (Bagatell 2010; Kapp et al. 2013); as central as other social identities such as their sexuality or race (Brown 2017). Under a minority model of disability, HFA and AS represent a distinct socio-political experience as neurominorities with wide ranging diversity (Altman 2001; Jaarsma and Welin 2012). 'Neurominority' is a relatively new term coined to describe those who fall under the neurodiverse model (Walker 2012). This study will examine how stress related to social stigma (e.g., Frost 2011) contributes to heightened rates of mental health problems experienced by the autistic community. We highlight the utility of social stress models (Meyer 2003; Meyer, Schwartz, & Frost, 2008) in understanding mental health and wellbeing in autism.

## Autism as identity

The biomedical model aims to cure disability (Rioux, Bach, and Roeher Institute 1994). Understanding disease from this model is only logical considering the need to treat and cure life threatening illness, however, it creates tension when considering disorders such as autism, dyslexia, and dyspraxia (Ward and Meyer 1999). The biomedical model relies on identifying disease and creating meaningful interventions to cure the person who is suffering (Bagatell 2010; Rioux et al. 1994). The traditional idea of autism is one in which a person does suffer (Kanner 1971). Viewing autism from a biomedical model has been opposed as it leads to dehumanizing research and treatment of autism (Tyler Cowen 2009). For example, it has been claimed that an autistic community cannot exist due to a central tenant of autism- a lack theory of mind, meaning autistic individuals are too introspective to want to or be able to form community connections (Barnbaum 2008). Similarly, it has resulted in work where they are compared less favourably to brain damaged monkeys (Bainbridge 2008). The minority model of disability formed partly as opposition to these notions.

The rise of the minority model of disability specifically challenged the medical model's notions of disability (Rioux et al. 1994; Smart 2006). The minority model of disability is underpinned by the notion that one can have something the medical model considers a disability, but in actuality, it is a society with restrictive notions of normal that creates disability (Altman 2001; Smart 2006). The Deaf community is an example of a community considered disabled by the medical model, and who reject that status, considering themselves to be a cultural group defined by the use of sign language (Smart 2006). The Autism Network International was the first self advocacy group created by and for autistic individuals, in part to combat the biomedical view of autism (Ward and Meyer 1999). Narratives of autistic self-advocacy are challenging the notions put forward from the biomedical model, and under the banner of neurodiversity, claiming minority status (Kapp et al. 2013).

Individuals who are affected have come to consider autism an intrinsic part of an identity (Bagatell 2010; Kapp et al. 2013). In fact, autism is sometimes as central to the identity of autistic individuals as race, ethnicity, sexuality, gender or nationality (Brown 2017), a claim often put forward by the Neurodiversity movement (Neurodiversity itself falling under a minority model). Thus, the minority model of disabilities may provide a basis on which autistic individuals can consider themselves within their own terms, and with dignity (Dunn and Andrews 2015). It has even been proposed that those with AS and HFA form an ethno-cultural minority akin to the Deaf community (Jaarsma and Welin 2012).

Thus, in the last two decades, what bio-medical researchers originally considered a disorder, has come to be a central feature of identity to some. Therefore, it is important to understand whether these minority identities leave autistic individuals vulnerable to the extra social stresses suffered by other minority communities as a result of social stigma and disadvantaged social status. Similarly,

## Stigma as Stress Resulting from Labelling Processes

The process by which stigmatization occurs begins with the process of labelling. A label is a definition, which categorizes a person by his or her characteristics (Link and Phelan 1999). Labelling in the case of AS/HFA involves a comparison of autistic individuals against their non-autistic peers and the assignment of meaning to those differences (Bagatell 2010; Elliman 2011; Hacking 2012). Most adults with HFA/AS will be aware of the differences between themselves and those not on the autism spectrum (Aylott 2000). Being aware of these differences is not an issue, until a value is assigned to them; whether it is perceived as a positive, neutral or negative difference. Labels absorb the meaning society gives them and thus, assigning value-based meanings to labels can often perpetuate stigma (Link and Phelan 1999); for example, a stereotype attached to autism is "loner" (Aylott 2000). In a study investigating the stereotypes non-AS peers held towards autistic individuals, 9 of the top 10

terms used to describe AS individuals were negative (Wood and Freeth 2016). A separate study found the behaviours central to autism were stigmatized (Butler and Gillis 2011). The effects of stigma can be long lasting, and limit the quality of life available to the stigmatized group (Markowitz 1998). A two year study on mental health and stigma showed that exposure to stigma designated the self-worth individuals afforded to themselves (Wright, Gronfein, and Owens 2000). Considering 9 out of 10 stereotypes afforded to autism are negative, there is the possibility of high exposure to stigma. Similarly, that this exposure has similar consequences.

The stigma afforded to autistic individuals likely explains why multiple studies have found a high risk of victimisation in the HFA/AS community; including physical, verbal, and sexual victimisation across the life-span from childhood (Little 2002), to adulthood (Rosenblatt and National Autistic Society 2008). Similarly, autistic individuals are more likely to face workplace discrimination in terms of unfair dismissal, workplace harassment, underemployment, and unemployment (Baldwin, Costley, and Warren 2014; Barnard et al. 2001; National Autistic Society 2012). Social rejection can also be internalized and selfperpetuating. For example, as a result of experiences of rejection, neurominorities may become embroiled in a negative self-concept, built upon the foundation of social rejection (Link et al. 1989). While the previously discussed research into victimisation and discrimination documents high rates of exposure among autistic populations, researchers have yet to focus on the impact of victimisation on the wellbeing of autistic individuals.

## The Potential Utility of Minority Stress Theory

The primary aim of the minority stress model is to explain disparities in health between majority and stigmatized minority groups (Meyer 2003). Social stress theory hinges on the idea that social disadvantage can translate into health disparities (Schwartz and Meyer 2010). Researchers hypothesize that decreased social standing leads to stigmatized minority groups being exposed to more stressful life situations, with simultaneously fewer resources to cope with these events. Social structure facilitates this process through acts of discrimination and social exclusion, which are added stress burdens that socially advantaged groups are not equally exposed to.

The minority stress model has most frequently been used to explain both mental and physical health disparities (Meyer 2003). Studies have consistently shown sexual minorities to have higher stress burdens, while simultaneously experiencing higher rates of poorer physical and mental health (Frost, Lehavot, and Meyer 2015; Herek, Gillis, and Cogan 1999; Meyer 2003; Meyer and Dean 1998); Cochran and Mays 2000; Gilman et al. 2001; Herek et al. 1999; Zietsch et al. 2011). To a lesser degree, the minority stress model has been used to highlight disparities in added stress and negative health outcomes in African-American populations (Feagin 1991; R. Williams and Williams-Morris 2000). Most pertinently for the study at hand, minority stressors have also been shown to impact on the severity of depressive symptoms experienced by those with physical disabilities (Brown 2017).

Four premises underpin the minority stress model. The first premise is that not all differences are discrepancies; an increase, for example, of certain illnesses with age, is a difference to be expected and is therefore not a discrepancy (Schwartz and Meyer 2010). The second premise is that the theory is based on the law of averages, and average effects. Although it is hypothesized that the social disadvantage influences the group in the entirety if a subgroup remains unaffected it does not falsify the overall theory (Schwartz and Meyer 2010b). The third premise is that the social stress theory applies causally to overall health rather than specific disorders. The fourth premise is that social stress theory is specifically about the sociological category of disadvantage produced by exclusionary social hierarchies, rather than anything specific about that group (Schwartz and Meyer 2010). In essence, the social group is devalued based on societal norms, thus, being in keeping with the minority

model of disability, which posits that disability (and co-morbiding psychological outcomes) stem from an inflexible society which has a preference for non-disabled individuals (Smart 2006). As shown in the paragraph above, support for this is shown by Brown (2017) who demonstrates the utility of understanding perceived stigma and coping in populations with physical disabilities, and how it may enhance our understanding of mental health outcomes.

Meyer and Schwartz discuss that it is unreasonable for any researcher to extend the model where there is no existing documentation for disparities between populations (Schwartz and Meyer 2010). A health disparity exists between autistic and non-autistic individuals, with those on the spectrum regularly found to have higher rates of physical and mental health problems (Baldwin and Costley 2016; Baldwin et al. 2014; Gillberg et al. 2016; Hirvikoski et al. 2016; Kamio, Inada, and Koyama 2013; Locke et al. 2010; Shefcyk 2015). A recent study showed an elevated risk of premature mortality for autistic individuals by on average two decades compared to non-autistic peers (Hirvikoski et al. 2016). The predominant cause of early death in HFA/AS was suicide (Hirvikoski et al. 2016). Rates of depression, suicidality, PTSD, and poorer mental health are all higher in autistic populations than non-autistic populations (Gillberg et al. 2016; Kerns, Newschaffer, and Berkowitz 2015; McManus 2009; Mikami et al. 2009).

#### **Current Study**

Applying the minoity stress model to understaning social factors relevant to health in the context of HFA/AS could begin to account for the additional stress burden faced by the autistic community, and potentially redefine what is known about autism and psychological wellbeing. The current study extended the minority stress model to examine the extent to which stigma-related stressors are associated with diminished wellbeing experienced by the HFA/AS population. We hypothesized that there would be a relationship between minority stressors and poorer mental health outcomes, such that greater amounts of reported minority stress would be associated with poorer mental health and wellbeing. In testing the potentially unique contribution that minority stress makes to mental health among HFA/AS individuals, we further hypothesized that associations between minority stress and mental health and wellbeing outcomes would persist above and beyond the contribution of general stressful life events known to impact the health of everyone, regardless of disadvantaged social status (Frost et al, 2015).

#### Method

#### **Participants**

An online survey was used to test the current study's hypothesis. Conducting the study using the internet allowed for a method consistent with the way in which autistic individuals communicate regularly; it has been noted that the internet allows for communication unfettered by social interaction (Bagatell 2010; Benford and Standen 2009; Hacking 2012; Jordan 2010). The survey, which is detailed below was circulated to autistic individuals via the Qualtrics survey system. Inclusion criteria were a minimum age of 18 and to consider oneself autistic. An official diagnosis was not necessary to participate. This decision was made in order to ensure that those who have been unable to access a diagnosis due to cost or personal circumstance, but still feel part of the autistic community, could participate (as has been done in other studies e.g. Kapp et al. 2013).

A total of 142 participants completed the survey. All participants that had extensive missing data (i.e., multiple variables were missing data) were removed (n= 31), resulting in a final sample of N = 111 participants. Table 1 presents the demographic information for the final analytic sample. Potential demographic limitations (e.g. gender) are discussed later.

## Procedure

A survey was developed using the measures described below to assess minority stress experiences in the autistic community. Non-probability sampling techniques were used. Recruitment was conducted within the following online groups: Aspergers Reality, Autistic Women's Association, The Aspie Cloud, Asperger Safe Room, Adults with Asperger Syndrome, Wrong Planet, Neurodiverse UK, Autism Action NZ, Autism Worldwide, Autistics UK, and Heart for Autism. It was distributed to AS/HFA community pages with permission from community moderators. Sampling evolved into a snowball technique as participants referred other people from outside these groups to the survey. After each participant had consented they completed a 14-minute survey, with the chance of winning a £50 voucher to a popular online retailer. This research received a favourable ethical opinion from the University of Surrey ethics committee prior to the commencement of data collection.

#### Measures

**Demographic information**. Participants reported their gender, age, and ethnicity. The options presented for gender were 'male', 'female', and 'other'. Where a participant selected 'other', they were asked for a perscriptor of gender they felt comfortable with. Age was reported by participants in a numerical entry box in the survey. Ethnicity was recorded in line with British census categories (as the research was primarily based in Britain). If none of the categories presented were relevant, participants could select the 'other' box, and were consequently asked to provide a descriptor for their ethnicity and race. Diagnosis was selfreported, with participants reporting if they had an official diagnosis, and, if so, providing the details of it following the procedure used in Kapp et al. (2013).

**General stressful life events.** (Adapted from Slopen et al. 2011) The stressful life events inventory was used to assess the impact of stressful life events on wellbeing. The inventory is a 'yes/no' inventory. The measure is not related to minority stress, but rather general life stress. The measure was coded in such a way that higher scores reflected more stressful life events in the 12 months prior to taking the survey. Questions included items such as 'you recently ended a long-term relationship'.

Victimisation and discrimination events. (Cronbach's alpha = 0.72, 8-items). Victimisation and discrimination measured the extent to which participants have faced discriminatory events in the last 12 months. The scale is on four points from never (0) to three times or more (3). Scores were coded (summed) in a way that higher scores reflected higher frequencies of victimisation and discrimination. Questions included items such as 'you were hit, beaten, physically attacked, or sexually assaulted'.

**Everyday discrimination.** (Williams et al. 1997; Cronbach's alpha = .87, 8-items). Experiences of everyday discrimination were measured with the everyday discrimination scale, which specifically measures covert discrimination. The measure used a four-point scale from often (3) to never (0) and asked questions such as 'in your day-to-day life over the past year, how often did any of the following things: People acted as if they thought you were not smart'. The scale was coded (summed) in a way that higher scores reflected greater everyday discrimination.

**Expectation of rejection.** (Meyer, Schwartz, & Frost 2008; Link 1987; 6 items, Cronbach's alpha = 0.90). Experiences of expecting rejection were measured using the 'Expectation of Rejection' scale. It asked you to consider your disability, gender race, and then presented items such as 'employers will not hire a person like you'. Participants responded on a scale that ranged from strongly agree (4) to strongly disagree (0). Scores were coded (summed) so that higher scores reflected a higher expectation of rejection.

**Outness.** (Adapted from Meyer et al. 2002; Cronbach's alpha = 0.71; 4- items). The outness scale measured the degree to which people on the spectrum disclosed to peers, colleagues, non-autistic friends, healthcare providers or family. Responses scaled from out to all (4), to out to none (1) The scale was coded (summed) so that higher scores reflected

higher outness. The wording of 'outness' was still used with regards to autism and disclosure because it is a term the community has adopted to describe disclosure (Jones, n.d.).

**Physical concealment.** (Cronbach's alpha = 0.83, 5 items). The physical concealment scale was designed specifically to measure the extent to which participants physically conceal behaviours associated with autism. It asked participants to recall whether they had had certain experiences in the last 12 months. The measure contained questions such as 'I have purposefully avoided disclosing being autistic on official documents (job applications etc.)'. Participants responded on a scale from never (0) to always (3) The measure was coded (summed) in such a way that higher scores reflected higher behavioural concealment.

Internalized stigma. (Adapted from Meyer and Dean 1998; Cronbach's alpha =0.84; 8 items). Used in an adapted format (specific to autism) to measure the extent to which individuals reject their status on the autism spectrum. It had questions such as 'you have felt alienated from yourself because of being on the Autism Spectrum'. It contained adjusted questions, of which the language was changed to relevant terms, but the concept remained the same. It also added two novel questions addressing certain unique aspects of HFA/AS. It was measured on a scale from strongly disagree (1) to strongly agree (5). It was coded (summed) in a way in which higher scores reflect more intense feelings of internalized stigma with regards to being autistic.

Wellbeing. (Keyes et al. 2008) The mental health continuum (MHC) was used in its three subscales; social (5 items), emotional (3 items) and psychological (6 items) wellbeing, with respective alpha ratings of .84, .91 and .87. The subscales were used individually to capture quintessential aspects of various forms of wellbeing (social, emotional and psychological) and examine how different forms of wellbeing inter-related to minority stress variables. They were coded (summed) in a way that lower scores reflected poorer wellbeing.

**Psychological distress**. (Kessler, 2003; Cronbach's alpha = 0.84) The psychological distress scale (K6) was originally developed by the US department of national health statistics. The K6 was designed to be sensitive around clinical thresholds for mental health disorders, with the short form (6 item) being 'as sensitive' as the ten-item survey (Wittchen 2010:10). Items on it included 'how often during the past month did you feel... nervous? ....fidgety? ...worthless?'. The response scale ranged on five points from all the time, to none of the time. It was coded (summed) in such a way that higher scores reflected higher psychological distress.

#### Results

#### **Descriptive and Bivariate Analyses**

SPSS 24 was used to conduct all analysis. Chi-Square tests were carried out to identify whether any differences of note (gender, ethnicity, autism type, age of diagnosis, age of identifying as autistic, diagnosis status, autistic symptoms, and mental health outcome variables) existed between those included and those excluded, however, none were detected;  $(p \ge .082)$ . Where there was a single missing value per case, the mode was computed and input; there were only 25 values missing across all cases, and exclusion from the sample based on one missing value would be extreme (all means and standard deviations can be found in Table 2).

Data were examined to identify whether distributions met parametric standards. All variables were normally distributed apart from victimisation and discrimination, which was skewed. To correct for skewness, this variable was transformed into a binary variable (Walters 2009). The variable was divided on the basis of exposure the specific items of the inventory: no exposure = 0; any exposure = 1.

Bivariate analyses are presented in (Table 2). Correlations of variables raised some concern regarding multicollinearity with independent variables having medium to high

correlation. Regression models with diagnostic information for multicollinearity were performed to further examine multicollinearity. Variance inflation factor scores (VIF) were all below 2, originally suggesting little to no multicollinearity. However, upon further inspection multicollinearity was identified within eigen values ( $\leq$ .01), condition indexes ( $\geq$ 15), and variance proportion scores ( $\geq$ .85). Theoretically, it is likely that minority stressors may not be independent, but rather have a relation to each other, causing multicollinearity. In order to address this issue, ridge regression (RR) was used to test the study hypotheses.

RR is an extension of linear regression. When there is a problem with multicollinearity, RR can be preferable to ordinary least squares (OLS) regression (Helwig 2017; Jacobucci, Grimm, and McArdle 2016; McNeish 2015). This is because OLS regression performs poorly with highly correlated variables, or where there are many predictor variables as it causes large prediction intervals, making the model uninterruptable (Helwig 2017). Ridge regression has been shown to be more effective at providing accurate results than other forms of non-penalised regression (OLS, stepwise etc.) when multicollinearity is present (Abram et al. 2016; Eledum 2016; Firinguetti, Kibria, and Araya 2017; Zhang and Ibrahim 2005). Introducing a small increase in bias can result in a large decrease in prediction error. It is a process of trade-off between bias and variance (Marquaridt 1970). The small 'penalty' ( $\lambda$ ) on the OLS estimators will reduce the variability of the estimators, making them more stable, easier to interpret, and more likely to transfer to new samples (Helwig 2017). Penalized regression has been highlighted as a good tool available to psychologists to increase the replicability of their research (Helwig 2017). Thus RR was chosen as the appropriate statistical method to approach the data with.

The penalty coefficient ranges from 0 (no penalty) to 1, on a .01 increment (Helwig 2017). The higher the penalty terms, the less variance, but also the smaller the beta coefficients. As such, it is a process of balancing. SPSS uses an iterative approach, which

runs multiple versions of the model using different penalties to find that which best balances bias, variance, and error. Using either cross validation or bootstrap .632 method of resampling is standard practice when using RR (hence it is built into SPSS as part of the RR algorithm) (a comprehensive explanation of the .632 method can be found in Efron and Tibshirani 1997). This paper uses the .632 estimator bootstrap method, as research has shown it to be more reliable (Efron and Tibshirani 1997; Linting et al. 2007). A randomised selection of fifty different cases were included in each iteration (with 1000 iterations run), and a mean standard error (MSE) computed from that. Similarly, the estimate of standard error on the standardized coefficients was calculated using bootstrapping with 1000 samples. This acts as a form of confidence intervals on the standardized beta coeeficients. No unstandardized betas are calculated because standardization of all variables is undertaken before RR is computed.

The demographics used in the analysis (ethnicity, gender, diagnosis status) were included as binary variables. They were coded into majority/minority cases (as seen in Meyer, Schwartz, and Frost 2008). Gender was coded as male 1, female and other 2. Ethnicity was coded as White British, other White 1, mixed/multiple, Black British, Asian, and other 2. Having a diagnosis was coded as 1, while no official diagnosis was coded as 2. Codes used were 1 and 2 as the ridge regression function in SPSS reads 0 as missing data. Similarly, due to this same issue, cases where a variable computed to a true 0 had to be recoded, as advised by the software manual (IBM n.d), to a very small non-0 value  $(1 \times 10^{-6})$ . This allowed it to be included in the analysis without adverse consequences on the result.

#### **Results of Ridge Regression Analyses**

The results of RR models predicting each of the mental health and wellbeing outcomes are shown in Table 3.

The regularization penalty applied to the social wellbeing model was  $\lambda$ =.12. Social wellbeing was significantly predicted by the behavioural concealment of autism, and expectation of rejection. The model accounted for 58% of the variance in social wellbeing F(38,72)=2.55, p<.001, R<sup>2</sup>=.58, MSE=.87. The significant standardized coefficients showed that lower levels of social wellbeing were associated with higher levels of expectation of rejection and behavioural concealment of autism. Gender was also associated with social wellbeing; however, the sample size difference between men and women (and other), meant this could not be explored further.

The regularization penalty applied to the emotional wellbeing was  $\lambda$ =.12. Emotional wellbeing was significantly predicted by internalised stigma and diagnosis status. The model accounted for 48% of the variance in emotional wellbeing, F(32, 78)=2.40, p=.001, R<sup>2</sup>=.48, MSE=.89. The significant standardized coefficients indicated that lower levels of emotional wellbeing were associated with higher levels of victimisation and discrimination, everyday discrimination, expectation of rejection and internalised stigma.

The regularization penalty applied to the psychological wellbeing model was  $\lambda$ =.26. Psychological wellbeing was significantly predicted by expectation of rejection, outness, stressful life events and everyday discrimination. The model accounted for 58% of the variance in psychological wellbeing F(32, 78)=3.57, p=.000, R<sup>2</sup>=.57, MSE=.85. The significant standardized coefficients indicated that lower levels of psychological wellbeing were associated with higher levels of victimisation and discrimination, everyday discrimination, expectations of rejection, and outness. Psychological wellbeing was also associated with ethnicity. The difference based on ethnicity could not be explored as the size of the sample differed too extremely.

The regularization penalty applied to the psychological distress model was  $\lambda$ =.22. Psychological distress was significantly predicted by everyday discrimination, expectation of rejection, outness, internalised stigma, and diagnosis status, the model accounted for 72% of the variance of psychological distress F(36, 74)=6.15, p<.001, R<sup>2</sup>=.72, MSE=.73. The significant standardized coefficients indicated that higher levels of psychological distress were associated with higher levels of everyday discrimination, expectation of rejection, outness, and internalised stigma, and having a diagnosis status.

### Discussion

The aim of this study was to investigate the utility of the minority stress model in understanding how stigma-related stressors contribute to mental health and wellbeing problems in the autistic population. Originally designed to investigate sexual minorities and ethnic minorities; the minority stress model (Meyer 2003) has provided a novel way to consider the experience of being HFA/AS. The findings suggest that autistic individuals experience an added stress burden in the form of minority stress. This stress burden is a potentially preventable factor in the mental health and wellbeing disparity seen in the autistic population. Minority stressors such as victimisation and discrimination, everyday discrimination, expectation of rejection, outness, internalised stigma, and physical concealment of autism consistently predicted diminished wellbeing and heightened psychological distress.

Thus, these findings provide the first, albeit preliminary, support that the minority stress model can be usefully extended to understand mental health and wellbeing problems faced by the HFA/AS population in that greater exposure to minority stressors are associated with poor mental health and wellbeing. Even further, it is important to note that these associations between minority stressors and mental health indicators persisted above and beyond the effect of general life stress and other demographic factors known to be associated with health and wellbeing (e.g., gender, race/ethnicity). Thus, these findings support previous

research indicating that minority stress has a unique and additive negative effect on health, which is not reducible to general stress alone (Frost et al. 2015).

Everyday discrimination was highly positively correlated with the expectation of rejection, which is something that should be investigated further. With each small act of discrimination it would, theoretically, make sense that expectations of rejection would increase. This association between smaller events of discrimination and the expectation for rejection is a sentiment that previous papers have expressed (Link and Phelan 1999; Stucky et al. 2011).

Outness, in the case of HFA/AS, was associated with poorer mental health in the form of lower psychological wellbeing and higher psychological distress. These findings run contrary to some findings from research on outness and wellbeing among sexual minorities, which indicate outness is beneficial for wellbeing (Daley 2010; Legate, Ryan, and Rogge 2017). A potential explanation for this discrepancy is that when HFA/AS individuals disclose their status on the spectrum it opens them up to *more* acts of discrimination. Within the minority stress literature the safeness of the environment is taken into account; in one situation outness may be therapeutic and in another, outness could be considered a risk (di Bartolo 2013). Such situational differences are highlighted by the 'Don't Ask, Don't Tell' (DADT) policy that was for a time implemented in the US armed forces (Davis 2010), where outness of LGBT status threatened one's career and safety within the army. The DADT policy affected the mental health of soldiers whether or not they disclosed, but more so when they did (Barber 2012). The potential wellbeing detriment of disclosure in autism could represent the effect of social punishment for being outside of the expected norm of neurotypicality. As previously discussed, the rate of unfair dismissal and bullying in the workplace is high for HFA/AS individuals (Baldwin et al. 2014). As tolerance and acceptence for neurodiversity and the autistic population increases, the direction of the

relationship between outness and mental health may change. While others have postulated that openness may reduce stigma (Corrigan, Kosyluk, and Rüsch 2013) the present results indicate that it can also be a factor in reduced wellbeing for the person 'coming out'. Eventually it may also represent a therapeutic process that will correlate with lower internalised stigma and better mental health as it does currently with LGBT communities in most Western situations (di Bartolo 2013).

Similarly, labelling theory (Link & Phelan 1987) may also explain why outness decreases mental health and wellbeing; post diagnosis, certain labels are attached to the individual and stereotypes often attached to autism are rarely positive, with 9 of 10 being derogatory (Wood and Freeth 2016). However, there was a significant negative relationship between psychological distress and diagnosis, with higher distress experienced among those with a diagnosis. Increased expectation of rejection in the diagnosed group may reflect the stigma that comes from having a proper diagnosis, or the stress of then having to hide this aspect of the self.

## **Clinical Implications**

In light of the results, the findings of this study, if upheld in further research, could mark a change in the way we consider mental health and wellbeing in the autistic community. Previously, poor quality of life (Barnbaum 2008; Kamio et al. 2013) has been intrinsically linked with autism, without the consideration that negative social factors (i.e., minority stress) may play a part in the wellbeing disparity experienced by autistic individuals. In Kamio et al. researchers investigating suicidal ideation in those on the spectrum found that three-quarters of their sample had suffered from bullying, yet still attributed suicidal ideation to the characteristics of autism (2011). This research has expanded the focus to include the wider implications of discrimination on members of the autistic community. These findings may shed light on the experience of autistic individuals in society and highlight the

consequences of the discrimination and victimisation highlighted in other research; for example, increased employment discrimination, sexual victimisation, bullying, isolation and homelessness (Baldwin and Costley 2016; Brown-Lavoie, Viecili, and Weiss 2014; Carter 2009; Heinrichs and Myles 2003; Homeless link 2014). This reframing of perspectives on autism can reflect a movement in which mental health problems such as depression, anxiety, and suicidal ideation are no longer considered inherent to autism (as in Kamio et al. 2013).

#### **Limitations and Directions for Future Research**

A possible limitation of the study is the translation of the measures from one minority community to another. While some of the measures were created for use with all minorities (expectation of rejection and everyday discrimination), others were originally designed for use with sexual minority communities and needed to be translated specifically for this study (outness and internalised stigma). The unique aspects of the autistic community may not have been reflected in these measures, and, rather than changing the language of existing measures, attempts need to be made to design new assessments of the unique qualities of the autistic experience 'from the ground up'.

Women were disproportionately represented in the study, which may decrease the generalizability of these findings. However, this is something that frequently happens in reverse, with males being overrepresented in autism research. The present sample could reflect the frustration that autistic females feel at the usual exclusion from research (Rynkiewicz et al. 2016; Shefcyk 2015). It is important to note that gender was controlled for in all analyses in order to partially account for this limitation. Future research needs to investigate the potential additive effects of multiple minority identities, such as being both autistic and an ethnic minority to see whether there are effects related to 'double discrimination' (as suggested by Grollman) (Grollman 2014). Similarly, other research (Brown 2014) has found a gender difference in the effects of perceived social devaluation on

mental health (albeit of physical disability), which might explain gender affecting social wellbeing in these results. A more in-depth analysis of that effect in a sample balanced for gender is needed.

It may be important to understand the relationship that everyday discrimination has on expectations of rejection and the place of labelling theory within the experiences of discrimination and expectation of rejection. This would require longitudinal research to understand the causal and cyclical relationships between these aspects of the minority stress experience. Such research has the potential to provide a better understanding of minority stress as the dynamic and situational model that it is theorized to be. Similarly, more research could be done on the meaning of diagnosis to unpick the relationship it has with the autistic person being labelled, and the societal context and perception of that label.

The prospects for future research stemming from this article are numerous. This study found increased exposure to minority stress was associated with poorer wellbeing within an autistic sample. By carrying out within-group analysis we can understand the impact of the actual social stress (Schwartz & Meyer 2010a). It provides an opportunity to understand the effect of exposure to minority stress on wellbeing in the autistic population. Every individual within the group may experience the process of social stress to different degrees. A between group study is also needed however, to fully test the full minority stress model.

Finally, although the present study contributes to the intergration of disability and stress literature (by demonstrating a clear relationship between minority stress and mental health in the autistic population), further work is needed to examine resilience factors that potentially buffer the negative effects of minority stress. Indeed, the minority stress model points to the potential buffering effect community connectedness may have and stress, stigma and disability literatures have been poorly integrated thus far (Brown 2010). Given the increasing community identity emerging in members of the HFA/AS population, theorizing and empirically testing the stress-ameliorating function of community connectedness for autistic people will likely prove useful.

## **Summary and Conclusions**

Although preliminary, this study represents the first to examine the applicability of the minority stress model to the autistic community, demonstrating the unique and additive impact of minority stress on mental health and wellbeing for members of the HFA/AS population. More research is needed to replicate these findings and address questions of causality in the association between minority stress and mental health for autistic individuals, along with stress-ameliorating factors in the autistic population.

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Characteristics	Percent n
Gender	
Female	72.1 82
Male	21.7 22
Other	6.2 7
Race/ethnicity	
British White	45.0 50
Other White	39.6 44
Mixed multiple	7.2 8
Asian	1.8 2
Other	6.3 7
Official Diagnosis	
Yes	70.3 78
No	29.7 33
Autism type	
Asperger Syndrome	82.9 92
Classic Autism	10.8 12
Pervasive Development Disorder	6.3 7
Age in years	M = 35.8 SD =11.

## Table 1: Sample demographics (N=111)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Ethnicity	1													
2 Gender	03	1												
3 Diagnosis status	.06	.06	1											
4 Stressful life events	.05	.15	.06	1										
5 Victimisation and	.05	02	.06	.42***	1									
discrimination														
6 Everyday	09	03	.02	.27**	.44**	1								
discrimination														
7 Expectation of rejection	21*	11	15	.13	.27**	.59***	1							
8 Outness scale	02	.10	.46*	.02	.03	.06	06	1						
9 Behaviour concealment	.06	02	.21*	.29**	.19*	.185	.08	.34***	1					
of autism														
10 Internalised stigma	05	19*	.11	.09	.19*	.28**	.18	.18	.42***	1				
11 Social wellbeing	.14	13	.04	02	06	32**	49***	13	12	06	1			
12 Emotional wellbeing	.13	.01	.18	06	01	37***	40***	01	09	24*	.65***	1		
13 Psychological	.14	07	.03	.01	01	35***	38***	22*	08	18	.72***	.71***	1	
wellbeing														
14 Psychological distress	06	.06	23*	.16	.11	.42***	.42***	.11	.10	.30**	56***	71***	68***	1
Mean				13.9	11.7	21.3	19.6	16.3	22.6	22.9	6.66	7.29	12.8	13.1
Standard deviation				2.07	3.72	6.82	6.41	4.40	8.12	6.98	5.94	4.44	7.89	5.20
<sup>c</sup> ** significant at <.001, *	*signific	ant at <.01	, *signific	ant at <.05 (	N=111)									

Table 2. Bivariate correlations, means, and standard deviations of independent and dependent variables <sup>c</sup>

		Social W	ell-Being		Emotional Well-Being				Psychological Well-Being				Psychological Distress (K6)			
Variables	β	ESE	df	F	β	ESE	df	F	β	ESE	df	F	β	ESE	df	F
Ethnicity	0.01	0.06	1	0.04	0.10	0.06	1	2.60	0.08*	0.04	1	4.18	0.03	0.05	1	0.51
Gender	0.20*	0.09	1	4.76	0.03	0.08	1	0.17	0.06	0.07	1	0.87	0.02	0.05	1	0.28
Diagnosis status	0.07	0.06	1	1.45	0.19	0.10	1	4.01	0.04	0.05	1	0.67	0.14*	0.07	1	4.14
Stressful life events	0.18	0.13	4	2.06	-0.12	0.17	2	0.46	0.06	0.13	3	0.18	0.08	0.09	2	0.80
Victimisation and Discriminat	0.19	0.18	3	1.09	-0.20*	0.12	3	3.05	14*	0.07	2	3.93	-0.10	0.09	2	1.44
Everyday discrimination	-0.22	0.21	5	1.12	24*	0.13	3	3.34	16*	0.10	4	2.56	0.23**	0.12	5	3.58
Expectation of rejection	44***	0.10	6	19.81	35***	0.15	7	5.21	50***	0.13	7	13.65	0.48***	0.17	5	8.30
Outness scale	20	0.14	5	1.98	-0.16	0.18	4	0.81	15*	0.09	6	2.63	0.15**	0.08	7	3.86
Physical concealment	22*	0.15	8	2.24	0.19	0.17	6	1.15	0.02	0.17	2	0.02	-0.06	0.10	6	0.38
Internalised stigma	0.15	0.18	4	0.71	26*	0.16	3	2.77	-0.15	0.16	4	0.88	0.26**	0.13	6	4.09

Table 3. Minority stress predictors of mental health and wellbeing outcomes

Note: \*  $p \le 0.05$ , \*\*  $p \le 0.01$ , \*\*\*  $p \le 0.001$ . Estimated standard error (ESE) calculated using bootstrap (1000). Lower scores in well-being reflect poorer well-being, higher distress scores reflect higher distress (N=111).

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