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Understanding stigma in autism: A narrative review and theoretical model

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Abstract

The experience of stigma by autistic people is relatively understudied, despite contributing to a range of poor outcomes and having an overarching impact on wellbeing. The current review of the literature synthesises research to determine what is currently known and presents a theoretical model of autism stigma. Autism stigma is primarily influenced by public and professional understanding of autism in combination with interpretation of visible autistic traits. Moderating factors include the quality and quantity of contact with autistic people, cultural factors, sex and gender, individual differences, and diagnostic disclosure. Stigma can reduce wellbeing as well as increase the presence of camouflaging behaviours, which mask autistic traits. Caregivers of autistic people can experience stigma by association, i.e. affiliate stigma, which can impact their own wellbeing. A variety of interventions and approaches to reduce stigma are discussed, including ‘autism friendly’ spaces, positive media representation, educational and psychosocial training for the public and professionals, as well as cultural and systemic shifts that foster inclusivity and recognise neurodiversity.

Introduction

The experience of stigma for minority groups is well recognised,^{1,2} with autism considered an identity-based minority.³ However, the specific experience of stigma for autistic people has been relatively understudied, with a bias towards the experiences of family members rather than autistic people themselves.⁴ The term stigma dates back to the ancient Greek practice of cutting or burning a mark into a person to brand them a slave, traitor or criminal; the mark of someone to be avoided.⁵ In modern usage, stigma is considered an attribute that is unfavourable and that seemingly discredits an individual, leaving them to be viewed as less valuable than the rest of society.^{1,5,6} Notably, this definition depends on a collective understanding of what is unfavourable, thus stigma is inherently socially constructed.¹

Stigma can be seen as an overarching term for problems of knowledge (i.e. ignorance), problems of attitudes (i.e. prejudice), and problems of behaviours (i.e. discrimination)⁷. Definitions of the interconnecting processes that contribute to or reflect stigma are varied, underlining the challenge of capturing this complex process. This review draws on Link and Phelan's seminal conceptualisation of stigma.⁸ They argue that the development of stigma derives from the culturally-driven detection and labelling of a difference (e.g. labelling people with a particular set of behavioural characteristics as autistic); which converges with other interrelated components to form stigma. The second component is the attribution of unfavourable stereotypes to the label (e.g. autistic people are unfriendly). From a social-cognitive perspective, this linking between a label and its stereotypes is key to the development of stigma, as stereotypes can implicitly affect how an individual perceives other people.⁹ The next component is the use of the label to cause a separation between 'them' and 'us' (e.g. autistic people vs. everyone else). The final component is loss of status and the experience of discrimination (e.g. not being hired or promoted because of being autistic). Status loss and discrimination can be perceived as behavioural outcomes of stigma; a consequence of being labelled, being classified as other, and being linked to undesirable characteristics. Experiencing status loss and discrimination lies at the heart of the inequality a stigmatised person faces and contributes to negative treatment at both personal and structural levels.^{7,8}

Limited knowledge and understanding has a critical role in the presence of stigmatised views as an individual is more likely to rely on reductionist labels and stereotypes, dichotomise into them vs. us, and ultimately behave in a discriminatory way. Attitudes and beliefs can be conceptualised as the deeply held cognitions that lead to the labelling, stereotyping, setting apart, and discriminating that contribute to stigma.⁸ Attitudes are often measured by directly asking people to state how much they endorse positive and negative attitudes towards autism.¹⁰ Alternatively, openness towards a fictional autistic adult or child is explored, for example, by asking participants to rate whether they would feel afraid of the autistic person.^{11,12} Stigma is traditionally measured using a measure of social distance, which is seen as a consequence of stigmatised views and conceptualised as the deliberate avoidance or exclusion of another person from social interactions.^{13,14} Stigma can be categorised into different types. Most commonly, the discussion of stigma refers to enacted or public stigma, which is the overt discrimination of stigmatised individuals.¹⁵ However, this review will also consider self-stigma, or felt stigma, which is when the stigmatised person turns the prejudice they experience onto themselves.¹⁶ This can include feeling shame in relation stigmatised characteristic(s), and fear of enacted stigma.^{16,17} Affiliate, or courtesy, stigma will also be discussed, which is stigma experienced by people associated with the stigmatised person e.g. family members (see Table 1).^{5,15}

Table 1: *A summary of the definitions of stigma.*

Term	Definition
Stigma	A socially constructed concept; any attribute that is seen as unfavourable and that seemingly discredits an individual, leaving them to be viewed as less valuable than the rest of society.
Public/Enacted Stigma	Discrimination or rejection experienced by a stigmatised person.
Felt/Self Stigma	The internalised prejudice experienced by a stigmatised person, including shame and fear of enacted stigma.
Affiliate/Courtesy Stigma	Stigma experienced through association with a stigmatised person (e.g. parents/caregivers and other family members).

Autistic people can experience loneliness and fewer friendships compared to neurotypical peers,¹⁸⁻²⁰ fewer friendships in adolescence compared to peers with other special educational needs,²¹ have more difficulties with education²² and employment,^{23,24} experience poor social integration,^{25,26} and face high rates of bullying²¹. These factors are associated with a reduced quality of life.²⁷ Whilst these experiences have been attributed to autistic traits, more recent thinking has also considered the impact of negative societal responses to autistic people in contributing to these outcomes.^{28,29} Reflecting this, interviews with neurotypical people have found that autism is perceived by some as violating ‘accepted societal norms’.³⁰

Autistic people encounter negative experiences in their everyday lives that likely reflect autism stigma. For example, neurotypical people are less likely to want to live in the same building as autistic people or to spend time together as friends,¹¹ and are also less likely to want an intimate relationship with an autistic person.³¹ At the extreme, autistic people can be dehumanised by neurotypical people.³² Autistic people describe autism stigma as destructive and at odds with their own conception of autism as a value-neutral category, like handedness and eye colour.³³ Accordingly, 15.4% of a

recent sample of 149 autistic adults report moderate to severe felt stigma,⁴ with experience of stigma being by reported by autistic adolescents and adults across a range of qualitative accounts.³³⁻³⁵ Alongside this, there is consistent evidence that affiliate stigma is experienced by the families of autistic people.³⁶⁻⁴⁵

The breadth of psychological and social issues relevant to autism stigma and the limited synthesis of this work drew us to a narrative review. The broad remit of a narrative review enabled us to consider a wide range of pertinent issues: factors that contribute to autism stigma, the impact of stigma for autistic people and their families, and possible interventions to reduce stigma. These findings will be conceptualised in a theoretical model of autism stigma (Figure 1). The model provides an overview for researchers interested in exploring the many facets of autism stigma and supports autistic people wanting to map their own experiences onto existing evidence. Importantly, when developing the model we considered the definition of stigma broadly and also incorporated relevant research on attitudes and acceptance, which are correlates of stigma and theoretically tightly coupled.^{8,46} Our narrative approach was underpinned by a thorough PubMed review of articles on autism (autis*) paired systematically with each of the following terms stigma, attitude, understanding, knowledge. We followed up relevant citations enabling our search to snowball and reach saturation. The model has been shaped by the findings, theory, and critical analysis within the references, as well as additional areas of research flagged as important by our initial search and included as part of our snowballing strategy (e.g. neurodiversity in autism).

Factors influencing stigma in autism

As detailed in Figure 1, the variables that contribute to autism stigma are public and professional understanding of autistic traits and expressed autistic traits. As previously mentioned, understanding has an overarching effect on the development of stigma. We also include expressed autistic traits, as stigma is fundamentally driven by a culturally-driven detection and labelling of a difference.⁸ We argue that it is from this intersection of understanding and observation of autism that other components of stigma occur. Moderating factors that influence the strength or direction of the

relationship between these variables and stigma include: the quality and quantity of contact, diagnostic disclosure, culture, sex and gender, and individual differences. Note that our model only includes the direct moderating effects on enacted stigma. These moderators are likely to have direct effects on both felt and affiliate stigma, but this is beyond the scope of the review.

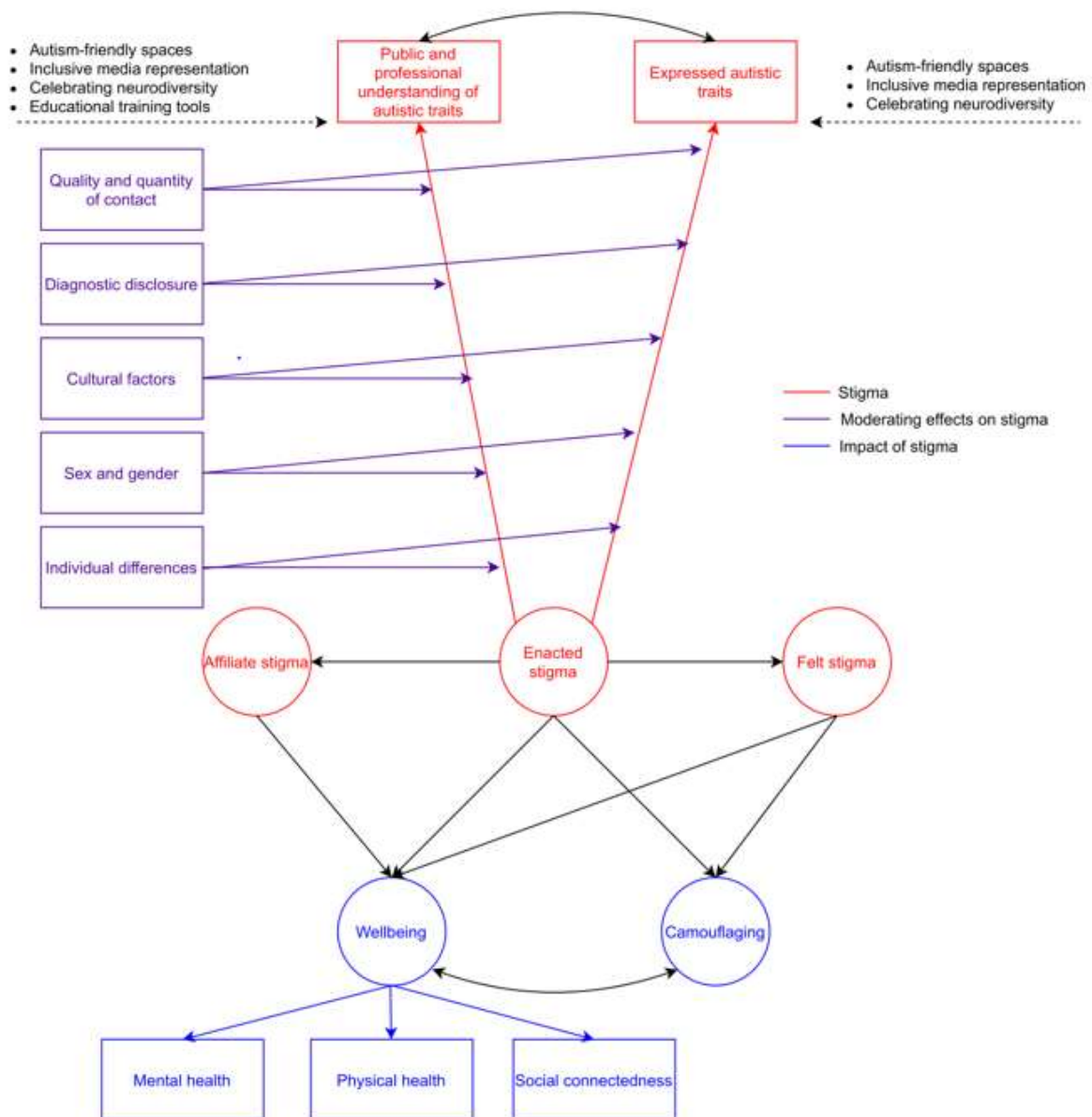


Figure 1: Theoretical model of the causes and impact of autism stigma.

Red circles indicate stigma, with Enacted stigma represented by the convergence of public and professional understanding of autism and expressed autistic traits (observed variables). Felt stigma and Affiliate stigma are experienced through Enacted stigma (black arrows). Purple rectangles indicate factors that have a moderating effect on the observed variables. Blue circles indicate the impact of stigma, including Wellbeing, measured by three observed variables, and camouflaging.

Black arrows indicate the direct effects between Enacted stigma and Wellbeing and Camouflaging, as well as the indirect effects through the effects of Affiliate and Felt stigma. The curved black double headed arrow illustrates covariance between public and professional understanding of autistic traits and expressed autistic traits, and between Wellbeing and Camouflaging. The bullet points above the dashed lines indicate interventions that may reduce stigma.

Public and professional understanding of autistic traits

When discussing understanding we are referring to a holistic conception and comprehension of autism that goes beyond factual or ‘book’ knowledge. For example, knowing that autism is diagnosed more in males would not be useful when wanting to support an autistic person struggling with sensory overload. However, studies have focussed on measures that probe knowledge, for example, discrete facts about aetiology, treatment or selected symptoms.^{13,47} Poorer public and professional knowledge of autism is often correlated with less positive attitudes⁴⁸ and more stigma,^{29,48-51} although null results also occur.⁵²⁻⁵⁶ Knowledge is also recognised by carers of autistic children as contributing towards stigmatised views.⁴⁴

Some surveys have shown encouraging levels of autism knowledge among the public.^{48,57,58} However, incorrect knowledge *is* present in the public and the impact of incorrect knowledge, even in the context of dominantly correct knowledge, is not understood. Some areas of misinformation include that autism is characterised by symptoms of other conditions,⁵⁸ that all autistic children show poor eye contact,⁵⁷ and that autistic people do not show affection or attachments.⁵⁰ Undergraduate students who incorrectly attributed unfavourable traits to autism were likely to have less positive attitudes towards autism regardless of the number of correct traits they identified.⁵³ This suggests certain misconceptions may dominate, even in the face of some correct knowledge. Another important consideration is the valence of the knowledge that is associated with autism. Eight of the ten characteristics that undergraduate students most commonly associated with autism had negative valence, with negative stereotyping likely to contribute to stigma.⁵⁹

There are also misconceptions and inadequate knowledge about autism amongst healthcare professionals.^{52,56,60-65} UK general practitioners displayed good knowledge of autism but only modest

confidence in their ability to work with autistic people,⁶⁶ which arguably highlights the limitations of factual knowledge in equipping professionals to engage effectively with autistic people. Teachers and childcare providers may also have poor knowledge and outdated beliefs about autism, particularly relating to aetiology,^{58,67-71} although teachers with more experience of autism have more knowledge.^{72,73} Some autistic pupils reported feeling stigmatised by their teachers and attributed this to being judged based on previous experiences with other autistic pupils.⁷⁴ These limitations have been partly attributed to insufficient training,^{64-66,75} with professionals with better knowledge and experiences less likely to stigmatise autistic children.^{44,49}

To fully explore the effect of autism understanding on autism stigma, fine-grained analysis is needed to disentangle what types of knowledge and understanding are most predictive of better attitudes and lower stigma. We argue that nuanced understanding, enabling someone to successfully identify an autistic person based on their pattern of behaviours, would be a better predictor than discrete facts. To this end, measuring understanding through identifying autistic people in vignettes or a video may be a more sensitive measure than fact endorsement. It would also be meaningful to extend understanding of autism to knowing how to best support autistic people. Consideration should also be given to what the autistic community think others should understand about autism. Reflecting this, a recent autism knowledge questionnaire that was co-produced by the autistic community found that the subsections around societal views and the experience of being autistic were predictors of autism attitudes in Australian adults.⁴⁸

Expressed autistic traits

Autistic people's difficulties in social communication are often physically expressed; examples include unusual patterns of eye contact, reduced facial expressions and sharing of emotions, and limited gesture use.⁷⁶ Restricted and repetitive behaviours can include motor mannerisms and unusual responses to sensory stimuli.⁷⁶ Sensory behaviours can be particularly prevalent outside the home in unfamiliar spaces,⁷⁷ and overwhelming sensory experiences can induce significant distress.⁷⁸ These visible autistic traits may lead to negative attitudes during first impression formation.^{28,79,80} When assessing first impressions using video clips, neurotypical people have perceived autistic people as

less attractive, more submissive, and more awkward than matched neurotypical counterparts.²⁸

However, first impressions were not negative when the speech transcript was presented without visual stimuli, suggesting the bias was driven by their expressive differences.²⁸

Some of these expressed differences can be particularly negatively perceived by the neurotypical population. Stereotyped or repetitive motor mannerisms, or ‘stimming’, were recognised by autistic people as being negatively judged by neurotypical people, making them feel devalued or ‘weird’.⁸¹ Autistic people have also reported that some autistic differences can be perceived as frightening to neurotypical people⁸² and that people sometimes associate autism with violent acts.³³ Relatedly, students in the US and Lebanon perceived disruptive autistic behaviours as more ‘dangerous’ than withdrawn behaviours, which prompted greater stigmatisation.¹⁴

Within our model (Figure 1), we have indicated a covariance between public and professional understanding of autistic traits and expressed autistic traits. This is because the social model of disability recognises the social construction within which autistic people exist, with poor understanding and attitudes from professionals and the public likely to affect expressed traits and possibly lead to elevated distress or discomfort for autistic people.⁸³ Similarly, the way that an autistic person behaves will inform public and professional insight into autism.

Moderating factors

The **quality and quantity of contact** that autistic and neurotypical people have with one another is an important consideration. Knowing and spending time with an autistic person is associated with more positive attitudes towards autistic adults and children.^{11,48,53,84,85} It is important to consider the distinct contributions of both the quantity and quality of contact, with both dimensions associated with more positive attitudes⁵⁴ and decreased stigma⁸⁶. However, quality of contact appears to be a more robust predictor of attitudes than quantity.^{54,86} This pattern of findings is congruent with data showing that people with autistic immediate family members have more positive attitudes,¹¹ and less stigma towards autism.^{13,29}

For neurotypical people, high quality interactions may lead to decreased anxiety and increased comfort around autistic people, which lays foundations for better understanding and consequently better attitudes towards autism.⁵⁴ Similarly, high quality interactions also support autistic people in feeling comfortable, which create better conditions for autism to be accurately understood.

Conversely, lack of understanding and unfavourable attitudes about autism from neurotypical people may lead to negative social interactions (e.g. being unwelcoming) that impact the interactions of autistic people (e.g. displaying wariness), limiting opportunities for quality social connections and potentially exacerbating stigmatised views.^{28,87} The quality of contact may be influenced by the issue of ‘double empathy’, whereby autistic and neurotypical people are mutually challenged in their understanding of one another due to fundamental differences in how each understand the world.^{88,89}

Autism is not associated with dysmorphology therefore autistic people’s ‘typical’ appearance coupled with their unusual behaviours may elevate stigma, with autistic behaviours understood as social deviance rather than reflecting an underlying difference or difficulty.^{30,90} Therefore, although more direct comparisons are required, existing research suggests that quality of contact has more impact than quantity.

Another important consideration is whether **diagnostic disclosure** may moderate how autistic people are perceived. The attribution model of stigma proposes that if a behaviour is perceived as controllable then negative reactions to a stigmatised individual will be greater as responsibility for their actions will be assumed.⁹¹ Related to this, the label of autism leads to more favourable first impressions of autistic people presented in video clips than when this label is not provided^{80,92} There is growing evidence that diagnostic disclosure can lead to more positive attitudes,^{55,93,94} more positive affective responses,⁹⁵ greater acceptance of inappropriate social behaviours,⁹⁶ as well as reduced stigma.⁹⁷ However, these findings are not universal. For example, knowledge of diagnosis can have a negative impact on first impressions of autistic people for those with high autism stigma,⁹⁸ whilst school children and adolescents do not modify their social distancing towards a fictional autistic peer when diagnosis is disclosed.⁹⁹ A recent scoping review concluded the fear of stigma was tied to the

reluctance of autistic people to share their diagnosis,¹⁰⁰ although concerns about judgement and misunderstanding have been attributed to both disclosing and not disclosing an autism diagnosis.^{33,101} The disconnect between experimental evidence of the positive impact of diagnostic disclosure and the lived experiences of autistic people warrants further exploration. One possible source of variance is the impact of pre-existing autism knowledge or understanding on the effect of diagnostic disclosure, with findings currently mixed.^{92,95} It is also relevant that diagnostic disclosure may also mediate how autistic people express themselves. A stronger autistic identity has been linked to a more open expression of autistic behaviours in everyday life, mediated by the extent to which the autistic person is open about their diagnosis.¹⁰² Further, autistic people may choose not to share their diagnosis in certain contexts,¹⁰³ which means they may behave differently across environments.

Another possible moderator is **cultural factors**. People in the USA held less stigma towards autistic people than those in Lebanon, Japan and China. However, whilst people in China and Lebanon had a lower understanding of autism, people in Japan had a similar level of knowledge to the USA.^{50,104,105} This aligns with the idea that dominantly collectivist cultures, where group cohesion is biased over the needs of the individual, may be more susceptible to stigma due to more ready adoption of culturally-defined norms.¹⁰⁴ However, an investigation of autism stigma in college students in Lebanon and the USA found that individual characteristics (e.g., previous contacts with autistic people) exerted a stronger influence on autism stigma than the country of residence.¹⁰⁶

Cultural differences can clearly exert significant influence. In South Korea, the lay classification of ‘border children’ recognises children in mainstream schools who would be described autistic by Western-trained clinicians.¹⁰⁷ This label is partly driven by parental desire to avoid autism stigma, with the cultural importance of academic success supporting their child’s ‘normalcy’.¹⁰⁷ Parents in China have described that the cultural belief that respect for the father is related to the prospects of the son, can mean parents do not want to disclose their son’s autism.¹⁰⁸ In other countries, the conceptualisation of autism as something other than a developmental disorder can leave communities vulnerable to stigma. For example, in Vietnam, autism has been variously conceptualised as a disease,

a ‘family problem’, and karmic demerit.¹⁰⁹ In parts of Africa, autism has been attributed to supernatural phenomenon.^{110,111} These types of beliefs not only lead to significant stigma, such as autistic children being asked to leave public transport or families being unable to rent accommodation,¹¹² but can also lead to inappropriate and sometimes dangerous ‘cures’ by traditional healers.^{110,111}

Cultural differences can also be perceived within a country among minority immigrant or indigenous communities. Somalian families in the UK report high levels of stigma towards their autistic children, leading to families hiding their child and delaying seeking support because challenging behaviours are not tolerated within their communities.¹¹³⁻¹¹⁶ There is prevalent autism stigma within Black American communities from diverse socioeconomic backgrounds, particularly related to denial and shame,^{117,118} as well lower levels of autism acceptance in Asian American communities.¹¹⁹ Aboriginal and Torres Strait Island community members in Australia that have autistic family members also report a high degree of stigma.¹²⁰ The experience of shame, which has strong cultural relevance, was commonly identified and linked with a reluctance to share the diagnosis. An additional challenge for minority groups is that autism stigma, which may have community-specific manifestations, is likely to interact with other stigma, such as those relating to religion, race, and ethnicity. Indeed, the starkest accounts of stigma by the Aboriginal and Torres Strait Island communities related to interactions with non-Aboriginal people.¹²⁰ Additionally, Black American parents have reported experiencing racism, including negative assumptions about their autism knowledge and family circumstances, within the diagnostic process.¹¹⁷ More nuanced investigation is needed to better understand the impact of culture and community, both within and across countries, on the experience of stigma for autistic people and their families. This could include direct exploration of whether there are contrasting experiences of autism stigma for families and autistic individuals within and outside of different community groups, and the extent to which additional forms of ‘otherness’ may compound stigma.

Although cultural factors are more easily associated with their possible impact on public or professional perceptions and understanding, it is also true they may influence the expression of

autistic traits. Reflecting this, there is modest evidence that the severity of some autistic traits may vary across some cultures.¹²¹

It is also important to consider the moderating effects of the **sex and gender** of autistic people. Whilst sometimes used interchangeably, sex focusses on the biological differences between males and females, whereas gender refers to the socially constructed roles, behaviours and attributes that society has designated for biological males and females.¹²² There is growing interest in delineating differences in the expression of autism based on sex and gender¹²² but gender and sex norms may also affect the perceptions of autistic people by neurotypical people. One qualitative study suggested that autistic females recognised pressures to fulfil gender stereotypes, including expected social skills, and that females groups were less forgiving of social ‘faux pas’.¹²³ Similarly, in a mixed methods study, autistic girls were more likely to feel like victims in friendship groups than autistic boys and neurotypical girls and boys, and felt punished for not ‘getting it’ socially.¹²⁴ These studies predict that autistic females would experience more stigma based on greater difficulty in aligning with gender norms. From the parent perspective, mothers of autistic children may be more vulnerable to experiencing autism stigma than fathers, including avoidance, hostile staring and rude remarks from the public.¹⁵ Again, this may relate to gender stereotypes, with a higher threshold of expectation set on mothers’ parenting. Typically, studies that include gender do not consider the broader spectrum of gender presentations, including transgender and nonbinary, who are overrepresented in autistic populations,^{125,126} which is an important consideration for future research.

Consideration should also be given to wider **individual differences** beyond an autistic person’s sex or gender. Individual differences related to the expression of autism are also relevant. For example, among undergraduates, disruptive autistic behaviours lead to more stigma than withdrawn behaviours,¹⁴ whilst parents of violent or aggressive autistic children are more likely to encounter stigma.¹⁵ From a different perspective, the autism stigma experienced by families may be greater if their child’s autism is less visible compared to children with more obvious additional needs, such as intellectual disability.¹⁵

In terms of individual differences among the public, there is converging evidence that females are less likely to have stigmatised views about autism,^{13,48,119} have higher levels of acceptance of autistic people,¹¹⁹ more positive attitudes,⁴⁸ and greater willingness for social closeness with autistic people.^{13,50} Higher educational levels are also associated with higher levels of acceptance¹¹⁹ and lower levels of stigmatised views.¹²⁷ However, education level is not a predictor in all studies.^{29,48} Age is generally not predictive of autism-related attitudes and stigma.^{29,48,119,127} Other relevant individual differences predictive of lower autism stigma include openness to experience, and decreased acceptance of inequality.¹⁰⁶

The impact of stigma

The potential effect of stigma on autistic people and their families is wide ranging and has an overarching impact on wellbeing.³ Wellbeing is a multidimensional construct, with stable wellbeing occurring when individuals have the psychological, social and physical resources to meet a particular psychological, social and/or physical challenge.¹²⁸ The insidious effects of stigma may erode at some of these resources, with deleterious consequences for wellbeing. As illustrated in Figure 1, stigma can affect wellbeing by influencing a range of factors including mental health, physical health, and social connectedness.¹²⁹⁻¹³¹ In addition, we consider the impact of stigma on behaviours adopted by autistic people to camouflage their behaviours, typically driven by a desire to ‘fit in’.^{132,133}

Wellbeing

Recent research has identified that the greater awareness of stigmatised status is related to lower levels of psychological wellbeing in autistic adults.¹³⁴ The lower social standing of stigmatised minority groups is believed to lead to exposure to more stressful life events, alongside fewer resources to manage these events.³ Autistic people have reported a wide range of stressors common to minority groups, including victimisation, violence, discrimination, rejection and felt stigma^{3,35,135}, which predicted heightened psychological distress, reduced wellbeing³ and reduced quality of life.¹³⁵

Similarly, only 7% of autistic adults felt accepted as an autistic person within society, with feelings of acceptance protecting against depression.¹³⁶ These findings are particularly relevant given the high prevalence of co-occurring mental health conditions in autistic people.¹³⁷

Felt and enacted stigma can lead to reduced access to healthcare, with implications for both mental and physical health.^{138,139} For example, there is suggestion that negative attitudes at university could stop autistic students from approaching support services.⁵³ Stigma can also lead to a reluctance to disclose an autism diagnosis in healthcare settings,¹⁴⁰⁻¹⁴² as well as in the workplace,¹⁴³ despite disclosure often being necessary for appropriate care or support.^{142,143} Similarly, stigma can lead parents to resist a diagnosis for their child.¹⁴⁴ Autistic people and family members have identified stigma and negative perceptions among healthcare professionals, alongside a lack of flexibility and unwillingness to make autism-specific adjustments.¹⁴² Therefore, stigma can affect the quality and appropriateness of health and social care received, with consequences for wellbeing.

The caregivers of autistic people are also adversely affected, with affiliate stigma correlated with anxiety and depression,^{37,145} poorer physical health,⁴² lower subjective wellbeing,¹⁴⁶ and fewer working hours.³⁹ A recent theoretical framework of the relationship between autism stigma and caregiver mental health suggests that there are both changeable factors (e.g. caregiver burden, self-blame, social isolation) and non-changeable factors (e.g. culture, financial burden), which both contribute to mental ill-health and stigma.¹⁴⁵

Aside from mental and physical health, the social connectedness that someone feels to their local and wider communities is also an important dimension of wellbeing.¹⁴⁷ The stigma and misconceptions of the neurotypical majority can lead to autistic people becoming socially isolated.¹⁴⁸ A dominant perception of autistic people is that they are not interested in social relationships.¹⁴⁸ However, many autistic people have a desire for meaningful friendships and relationships but struggle to obtain them.¹⁴⁹⁻¹⁵¹ Dissatisfaction with social support¹⁹, less social contact¹⁵² and less social connectedness¹⁵³ have all been associated with the experience of loneliness for autistic people. In turn, loneliness has been associated with depression and anxiety for autistic people across multiple studies,^{131,152-154} as

well as with poorer life satisfaction and self-esteem.¹³¹ In contrast, feelings of greater social connectedness, more time spent with friends and greater levels of perceived social support have all been associated with better wellbeing among autistic college students.¹⁵⁵ However, the heterogeneity of autism means that assumptions should not be made about the desire for social connectedness. Those who want more social connectedness are arguably more likely or able to voice their social preferences, so it is easy to forget those who are more passive and retiring, including those who prefer aloneness and do not want intrusion. There should be understanding and acceptance of autistic people whatever their social style.¹⁵⁶

For family members, parents report friends asking them not to bring their autistic children to social gatherings or judging their parenting.¹⁵⁷ More generally, parents can find reactions from members of the public difficult and have reported feeling embarrassed in public when their autistic child does not behave in socially acceptable way.⁷⁸ These experiences may partly explain why the degree of affiliate stigma associates negatively with participation in community events for parents of autistic children,¹⁵⁸ as well social disconnect from family and friends.³⁹ In summary, autism stigma can have negative effects on the mental and physical health of autistic people and their families, as well as leading to reduced social connectedness. These factors all contribute to reducing wellbeing within autistic communities.

Camouflaging

Stigma may also be a driver of the behaviours that autistic people choose to present to society, with consequential impact on mental health and identity. Defined as ‘camouflaging’, some autistic people dampen down or mask their autistic traits to try and appear more neurotypical and better manage social situations.^{132,133} This relates to the concept of ‘compensation’ in autism, whereby some autistic people show more ‘typical’ social skills than their underlying social cognitive difficulties would predict.¹⁵⁹⁻¹⁶¹ Compensating for underlying difficulties and camouflaging certain behaviours is mentally taxing and may result in fatigue,^{132,160,162} poorer mental health,^{130,133,140,162-164} educational underachievement,¹⁶² and suicidality.¹⁶⁵ The drive to behave neurotypically can also delay diagnosis,

delaying not only access to support but making the autistic person vulnerable to stigma through being less well understood.^{92,95,96,157,166} Some motivations for camouflaging appear to reflect the pursuit of fulfilment, such as the desire for meaningful relationships.^{130,132,160} However, other behaviours often relate to societal norms, including fear of rejection or bullying, a pressure to conform,¹⁶⁰ and awareness of being in a ‘social minority’.¹⁶⁷

Camouflaging has resonance with the concept of ‘concealment’, which is a way that stigmatised groups have protected themselves from discrimination.¹⁶⁸ Recently, autistic people have described the camouflaging of their autism as a direct response to concerns about experiencing stigma,^{33,169} as well as feelings of shame, which reflects felt stigma.¹³⁰ In this context, camouflaging behaviours have been described as a ‘normalising artifice’ in which the stigma of autism is transformed into the mask of autism.¹⁷⁰ Reflecting this, greater perception of autism stigma was associated with greater camouflaging in a sample of autistic adults, which has been interpreted through Social Identity Theory as a way of associating with the higher-status neurotypical majority.¹³⁴ However, although there is a relation between a stronger autistic identity and reduced camouflaging, some autistic people experience an inconsistency; being proud of and strongly identifying as autistic whilst also camouflaging to fit in.^{130,134,162} Better understanding of this apparent paradox could be helpful in supporting autistic people to make informed choices about the strategies they adopt to align with the neurotypical majority. In summary, there is converging evidence that camouflaging behaviours can have a deleterious effect on mental health, and they are tightly coupled with protecting the self from the negative consequences of autism stigma.

Reducing stigma

There are various approaches that may reduce the stigma experienced by autistic people and their families, although there has been relatively little research. In Figure 1 we have included examples of interventions that may bring positive change for the autistic community. For ease of illustration, we have focussed the primary impact of the interventions on contributors to enacted stigma: public and

professional understanding of autism and expressed autistic traits. However, these interventions are likely to have wider impact on, and interact with, other components of the model.

Autism friendly spaces

Autism-friendly spaces are ones in which the ‘person-environment’ fit is enhanced,¹⁷¹⁻¹⁷³ including making a space more socially comfortable (e.g. availability of a quiet room; agreed expectations about social interaction) or physically comfortable (e.g. appropriate lighting) alongside more generic adaptations such as improving the predictability of an environment. A relevant overarching approach is Universal Design, in which environments are developed as inclusive for all at their earliest conception, rather than being subsequently modified.¹⁷⁴

Autistic people have reported that socialising can be particularly difficult when neurotypical family and friends do not consider their preferences, with some activities being inaccessible due to environmental challenges.¹⁶⁷ Further, the inappropriateness of many school environments has been described as a barrier to inclusivity, including issues relating to unpredictability, sensory experiences, and social pressures.^{74,175} Adaptations to environments gives more opportunity for neurotypical and autistic people to share spaces. Although yet to be empirically tested, we argue that autism-friendly spaces can improve understanding of and attitudes towards autism by enabling autistic people to better integrate with the wider community. Further, autism-friendly spaces are less likely to invoke distress, thus enabling autistic people to be their true selves. We argue this will enhance the quality of interactions with autistic people, and consequently reduce stigma.^{54,106} Thus, although the driver of autism-friendly environments is to make spaces more comfortable for autistic people, there may be wider benefits relating to inclusivity and stigma reduction.

Increased inclusive media representation

Knowing someone with autism is associated with more positive attitudes towards autism^{11,48,53} and less stigma.^{11,13,29} This ‘knowing’ of autistic people could be partly achieved by greater and better media representation. Negative reporting of autism is correlated with negative attitudes¹⁷⁶ but the

media representation of autistic people is often negative.¹⁷⁷⁻¹⁸⁰ There has been a call for more accuracy in portrayals of autism in the media, although achieving a balanced message is difficult given the heterogeneity of autism.¹⁸¹ Positive portrayals are also beneficial for autistic people and their families.¹⁴⁴ Therefore, positive autistic role models and representation of the diversity of autistic experience is likely to improve understanding and reduce negative attitudes, ultimately reducing autism stigma. Additionally, positive media representations may support autistic people in expressing themselves and reduce the need for camouflaging.

Educational and psychosocial training tools

Another approach is to formally educate the public and professionals about autism. Online training using PowerPoint has significantly increased knowledge and decreased stigma in students.^{13,50,182,183} However, it is unknown whether these positive changes would be sustained over time, nor whether the training would translate to real-life behaviours. With respect to the impact of training on real-life, a recent study investigated the effect of an autism acceptance training video on young adult males who subsequently engaged in a conversation with an autistic social partner.¹⁸⁴ Both partners reported more interest in spending time with each other compared to dyads where the neurotypical partner had not had the training, suggesting training had a relational effect. This supports a previous study where the video had a positive effect on reducing self-reported autism stigma in undergraduates.¹⁸⁵ However, the positive effects of the video on real-life interactions did not extend to all measures of interaction quality,¹⁸⁴ and the video did not affect an implicit bias towards associating autism with stigma-related attributes.¹⁸⁵ For children, the 'Understanding Our Peers with Pablo' programme encompasses story books and animations to teach about autism and reduce autism stigma. It improved attitudes towards unfamiliar autistic peers but did not enhance attitudes towards familiar autistic peers compared to a control group.¹⁸⁶ Additionally, behavioural intentions were not improved and thus stigma still prevailed, which is consistent with previous research that has used a similar intervention with adolescents.^{187,188} Therefore, although studies addressing stigma can bring positive change, the outcome measure is an important consideration. An explicit shift in attitudes may not be a sufficient determinant of a more embedded change in implicit beliefs or behaviours.

A recent survey of neurotypical people found that knowledge of what it could be like to have autism predicated more positive attitudes towards autism.⁴⁸ First-hand experience of an autistic perspective may help neurotypical people understand that their actions may align with an autistic person when they have similar experiences,¹⁸⁹ reflecting the issue of double-empathy. Technological innovations offer opportunities for providing this perspective. ‘Auti-Sim’ is a simulation of sensory overload designed to give neurotypical people a first-person experience of challenges autistic people face.¹⁸⁹ Using the simulation increased perspective taking compared to watching a simulated experience or reading a vignette, and heightened perspective taking was associated with greater emotional concern and helping intentions. However, there was no difference in explicit attitudes towards autism. Similar approaches include videos designed to illustrate the first-hand experiences of autistic people in their everyday lives e.g. during a short walk.¹⁹⁰

Looking forwards, there may be mileage in drawing upon existing resources that target the implicit, or unconscious, bias that individuals can hold towards marginalised groups.^{191,192} Further, comprehensive programmes that include whole organisations, such as the Welsh Government’s Learning with Autism whole-school training programme¹⁹³, may engender greater attitude change due to the enhanced capacity for a cultural shift. Importantly, participatory input from autistic people in adapting an online training tool has led to the tool being more effective at changing autism knowledge, autism stigma and attitudes towards inclusion, compared to a version of the training where there was no participation.¹⁸² This therefore underlines the value of including autistic people in the development of training tools.

Neurodiversity

Arguably, autism stigma may be best reduced by a fundamental shift in the way autism is perceived by society. The neurodiversity movement celebrates autism for the differences it brings to society and for being an integral part of autistic people’s identities, similar to race, sexuality or nationality.^{29,194} The term ‘neurodiversity,’ initially adopted by members of the autistic community,¹⁹⁵ is now

recognised by many other neurodivergent groups.^{196,197} It is encapsulated within the minority model of disability, which emerged as a direct challenge to the biomedical model of disability, with its focus on pathology and cure.^{3,194,198} A central tenant of the minority model is that society's restricted conceptualisation of 'normal' creates disability.³ It has close ties with a social-developmental account of autism that argues the development and wellbeing of autistic individuals is significantly shaped by misperceptions of the neurotypical majority.⁸⁷ In essence, neurodiversity is the recognition of the range of natural diversity that is found within human development.¹⁹⁹ Adopters of neurodiversity reject the medical model of autism as 'deficit' in favour of autism as 'difference', which contributes positive diversity to society.^{29,194} Importantly, the onus on embracing neurodiversity should not be placed solely with autistic people and their families. Autistic people may feel more positive self-identification through identifying with neurodiversity but the power of neurodiversity to engender meaningful societal change depends on its wide adoption. Recently, there has been a call to members of the autism research community to engage with the tenants of neurodiversity and bring about a paradigm shift in autism research.¹⁹⁹

Having views aligned with the neurodiversity model is associated with lower stigma towards autistic people.²⁹ Autistic identification is positively related to positive self-esteem, and is related to lower levels of depression and anxiety.²⁰⁰ The neurodiversity movement aligns with the ownership many autistic people have taken of language used to describe them, with endorsement of disability- or identity-first language.^{194,201,202} Disability-first language (e.g. autistic person) is considered less stigmatising, partially because person-first language (e.g. person with autism) could imply the identity is shameful and partially because person-first language is not used in context outside of disability.^{33,202,203} However, not all autistic people or their families prefer identity-first language²⁰¹ and differences in preference should be considered. There has been a call for researchers to avoid ableist language, which carries an implicit assumption that disabled people are inferior to others,²⁰⁴ and to adopt the term 'autism spectrum condition' over the potentially more stigmatising 'autism spectrum disorder'.

It is important to note that identity with the autistic community can be ambivalent for some, with the benefit of finding a sense of belonging existing alongside internalisation of the autism stigma.^{101,170}

The visibility of positive autism messages is therefore key and the embracing of neurodiversity can be seen in narratives in which autistic people call for acceptance of autistic behaviours, such as stimming.⁸¹ Other activities to support neurodiversity include events that showcase the achievements of autistic people, particularly when designed by autistic people.¹⁹⁰ The neurodiversity movement therefore has potential to improve public and professional understanding of autism, while also creating a culture where autistic people feel more able to express their true selves. It may also reduce the need to camouflage autistic behaviours, bringing co-occurring improvements in mental health.

Conclusion

Our synthesis of the literature has presented a model of autism stigma designed to promote understanding and further research of the difficulties people within the autistic community may face in finding acceptance. A truly nuanced exploration of autism stigma should take an intersectional approach, in which the wider social and cultural context and other forms of stigma can be accommodated.²⁰⁵ It is imperative that future autism sigma research includes participation from those with lived experience,^{29,199,206,207} not least because to leave the autistic community out of the research process perpetuates a ‘them’ and ‘us’ culture that reinforces stigma. Consideration must be given to including a diverse range of autistic community contributors, including those who may not typically engage with research.²⁰⁸

Importantly, we are not assigning responsibility to the autistic community for their stigma. Rather, we are reflecting theoretical understanding that the development of stigma is driven by the cultural framing of difference and the insidious effects of labelling this difference.⁸ For autism, decades of converging research support the reality of patterns of social communication differences and restricted and repetitive behaviours, which can cause challenges in everyday life. However, when we refer to a label as a ‘condition’ or ‘disorder’, we are locating the referent in the stigmatised person, rather than

recognising that the label has evolved because of its social significance and as a product of social processes.⁸ There is clearly a value to labelling, not least because it creates a shorthand for society to recognise and address an individual's needs. However, by labelling a 'difference', ostensibly to provide support, we are creating challenges for the labelled. There is no easy solution to this conundrum. An interesting counterpoint to this has been the neurodiversity movement and the reclaiming of identity by autistic people. Many autistic people are communicating that their autism 'is' them and not something separate,²⁰² which at face value is counter to approaches that advocate distancing from a stigmatised label.⁸ The neurodiversity movement may therefore support a shift in both the power and value of autism labels, with the potential to reduce autism stigma. Additionally, neurodiversity may provide a valuable framework in which to develop a novel programme to challenge and reduce felt stigma in autistic people.

Author contribution statements

CJ and AT were involved in the conceptualisation of the manuscript and wrote the original draft. CJ led on the development of the model. KL reviewed and edited drafts of the manuscript. All co-authors have reviewed and approved of the manuscript prior to submission. The manuscript has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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