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Development of stigma-related support for autistic adults: Insights from the autism community

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Abstract
Many autistic adults experience public stigma and some internalise this stigma with negative effects on their mental health. While efforts to reduce public stigma are paramount, change can be slow, and interventions to prevent internalised stigma may also be needed. Using a mixed methods online survey, we gathered the views of 144 autistic adults and parents/caregivers of autistic people in the United Kingdom on whether a stigma-related support programme for autistic adults is needed and, if so, what it should 'look' like. Quantitative data (summarised descriptively) showed that most participants felt it was important for autistic adults to have support in managing stigma and revealed diverse preferences in terms of programme delivery, underscoring the need for flexibility. Using reflexive thematic analysis, four main themes were identified from the qualitative data: (1) 'We need to change society not autistic people', (2) 'Stigma is difficult to manage alone', (3) 'Focus on positive, practical support', and (4) 'There is no one size fits all approach'. We discuss the important implications our findings have for how future interventions in this area are framed and delivered.

Lay Abstract
Many autistic adults experience public stigma, which refers to negative attitudes and treatment from others. Because of that, some autistic adults may also apply unhelpful beliefs to themselves, which is known as internalised stigma. There is some evidence that both public stigma and internalised stigma are linked to poorer mental health in autistic adults. Clearly, it is crucial to change how society thinks and acts towards autistic people. There are several programmes that are trying to do this. But as change can be slow, support may also be needed to help autistic people cope with and challenge stigma. Using an online survey, we gathered the views of 144 autistic adults and parents/caregivers of autistic people in the United Kingdom on whether a stigma support programme for autistic adults is needed and, if so, what it should 'look' like. Most participants felt it was important for autistic adults to have support in managing stigma because of the harmful effects that stigma has on mental health and the challenges that autistic adults face in disclosing their diagnosis. However, participants were also concerned that such a programme could convey the message that autistic people, rather than society, need to change. Participants suggested that the programme should be positive and practical, helping autistic adults to understand and accept themselves, as well as learn context-specific strategies for responding to stigma and/or disclosing their diagnosis. They also stressed that the programme should be flexible and inclusive, recognising that autistic adults have very different needs and preferences.

Keywords
autistic adults, consultation survey, internalised stigma, intervention development, stigma

Introduction

Stigma is a multi-level phenomenon. Public stigma refers to a process in which differences are labelled by society, and labels are associated with negative stereotypes, leading to discrimination and status loss for labelled individuals (Link & Phelan, 2001). In addition to the direct effects of social devaluation, labelled individuals may also internalise stigma with further harms to their self-esteem and

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self-efficacy (Corrigan et al., 2006). Internalised stigma is a process that involves becoming aware of public stereotypes, agreeing with those stereotypes, and applying those stereotypes to oneself (Corrigan & Rao, 2012). This process of internalisation is particularly insidious as, although it originates from social attitudes, it 'can become self-generating and persist even when individuals are not experiencing direct external devaluation' (Meyer & Dean, 1998, as described in Frost & Meyer, 2009, p. 2). In response to stigma, some may seek to dissociate themselves from the stigmatised group/identity, while others may choose to strongly associate themselves with the group/identity and advance social justice, akin to how the autistic self-advocacy and neurodiversity movements have reclaimed and reframed autism as a positive identity (Leadbitter et al., 2021).

Autistic adults commonly report perceiving, anticipating and experiencing public stigma (Han et al., 2022). Many autistic adults are aware of negative stereotypes that society has of autistic people, and some apply these to themselves (Botha et al., 2020; Leedham et al., 2020; Punshon et al., 2009). There is evidence that both public stigma and internalised stigma are associated with poorer mental health in autistic adults. Less perceived autism acceptance from external sources and less personal autism acceptance has predicted greater levels of depression (Cage et al., 2018). Higher exposure to stigma-related stressors such as victimisation, everyday discrimination, expectation of rejection, internalised stigma, concealment, and disclosure has also been linked to lower levels of wellbeing and higher psychological distress (Botha & Frost, 2020). Interestingly, both concealment and disclosure have been negatively correlated to wellbeing, illustrating what has been called a 'double bind' by autistic adults where either option may have adverse outcomes (Botha et al., 2020).

Clearly, it is paramount to address public stigma, as society is the locus of the problem and should be the locus of change. There is an emerging body of literature on interventions designed to reduce autism stigma at the interpersonal level, including education-based interventions that provide factual information about autism, and contact-based interventions that facilitate interaction between autistic and non-autistic people. Generally, interventions solely based on education have reported larger changes in knowledge of autism than stigma towards autistic people, suggesting that the latter is more resistant to change (Gillespie-Lynch et al., 2015; Obeid et al., 2015; Someki et al., 2018). Interventions combining education with high-quality contact have shown promise for improving attitudes and behavioural intentions towards autistic people, but it remains unknown if these effects will persist over time and extend to real-world environments (Dachez & Ndobo, 2018; Gillespie-Lynch et al., 2021; Jones et al., 2021). Thus, while public stigma still exists, some autistic individuals may also benefit from efforts to address stigma at the individual level to prevent internalised stigma. To the authors' knowledge, there are currently no interventions that specifically provide stigma-related support for autistic adults, although such interventions exist for other stigmatised groups.

In the mental health field, several types of internalised stigma interventions have been identified, including Healthy Self-Concept, Self-Stigma Reduction Programme, Ending Self-Stigma, Narrative Enhancement and Cognitive Therapy, Honest Open Proud (HOP), and Photo-Voice (Yanos et al., 2015). These interventions draw on some common techniques, such as using psychoeducation to correct myths, cognitive reframing to counter negative self-beliefs, and narrative approaches to make meaning out of personal experiences. However, HOP differs from the other interventions by focusing on supporting individuals to reach careful decisions around disclosing their diagnosis, rather than directly targeting internalised stigma (Corrigan et al., 2013; Scior et al., 2020). HOP was originally designed as a peer-led group programme involving three weekly sessions that guide participants in weighing the pros and cons of disclosure in different contexts and crafting an empowering personal narrative. A recent meta-analysis found that HOP had significant positive effects on stigma stress as well as smaller, statistically non-significant effects on self-stigma and depression in individuals with mental health problems (Rüsch & Kösters, 2021).

Within the disability field, research on stigma interventions at the individual level is still in its infancy. A pilot study adapting HOP for people with dementia and their carers found that the intervention was feasible in community settings in central London but not in healthcare settings in outer London, possibly due to organisational factors and transportation barriers (Bhatt et al., 2020). Nonetheless, qualitative results suggested that participants who attended the adapted HOP intervention found it acceptable and felt they benefitted from peer support. A novel programme, Standing Up For Myself (STORM), has also been developed to empower adults with intellectual disabilities to manage and resist stigma (Scior et al., 2022). STORM was delivered in a peer-led group format with four weekly sessions and a follow-up session, during which participants discussed experiences of stigma and planned their responses to stigma. Preliminary evaluation showed that participants valued the opportunity to process difficult events and emotions, strengthen connection with others, and enhance self-advocacy and self-efficacy. At present, it is unknown whether it may be appropriate to adapt such programmes for an autistic population, or whether there is a need to develop a new stigma support programme for autistic adults.

The Medical Research Council (MRC) guidance for developing and evaluating complex interventions has emphasised the importance of engaging stakeholders to maximise the potential of producing an intervention that is acceptable and effective (Skivington et al., 2021). In the development of an intervention for autistic adults, autistic adults are the primary stakeholders and their perspectives should be prioritised as they are experts on their own experience. In addition, we also considered caregivers as secondary stakeholders as some autistic adults may require their support to participate in an intervention, and some studies on interventions for autistic adults have reported caregiver involvement as a facilitator to success (Laugeson et al., 2015; Mandelberg et al., 2014). Furthermore, it is well-documented that parents also experience public and internalised stigma in association with their autistic children, which means that they may be able to share relevant insights on autism-related stigma (Mitter et al., 2019; Papadopoulos et al., 2019). From here on, autistic adults and their parents/caregivers are collectively referred to as 'the autism community' (as per Pellicano et al., 2014). It is well recognised that meaningful involvement of the autism community can improve the quality of autism research and contextualise findings in a real-world setting, thereby facilitating the translation of research into practice (Fletcher-Watson et al., 2019; Keating, 2021). Thus, the aim of this study was to conduct a survey to examine the views of the autism community on whether a stigma support intervention for autistic adults is needed and, if so, what it should 'look' like, in order to guide future research and intervention development.

Methods

Materials

An online consultation survey was developed, which comprised a mix of multiple choice and open-ended questions. The survey began with a question asking participants to select the capacity in which they were completing the survey (i.e. as an autistic person, as a parent/caregiver of an autistic person, or both). Autistic adult respondents were additionally asked to state whether they had a formal diagnosis of autism, and the extent to which they were open about their diagnosis/identity (e.g. not open, selectively open, open, or very open). The survey was then organised into three sections. Section 1 collected participants' demographic information (gender, age, ethnicity), and views on whether it was important for autistic people to have support in managing stigma (on a 5-point scale from 'definitely not' to 'definitely yes'). Section 2 presented a short video describing the HOP and STORM programmes to facilitate discussion on the topic, followed by questions asking which (if either) programme would be appropriate for autistic adults and, if so, how to make the programme more suitable for autistic adults. The third and final section of the survey sought to identify design preferences, including delivery format (e.g. small group, one-to-one, guided self-help; online, in person, or both). Perceived barriers and facilitators to participation were also asked about (e.g. whether having a trained autistic facilitator might help autistic adults to take part; whether not feeling comfortable/ready to talk about their diagnosis might prevent participation). A copy of the survey is available as supplemental material.

The survey materials were developed by the first author, with input from autistic members of the team who made suggestions to improve accessibility, such as including a preview of the full survey in the participant information sheet and a transcript of the video in the survey. The autistic team members also emphasised the importance of providing a clear justification for why a stigma intervention would target the stigmatised group rather than the stigmatisers. As such, clarifications were made to the rationale for the research. Specifically, it was emphasised that ongoing efforts to reduce public stigma are indeed crucial, but as change can be slow, programmes that empower autistic people to cope with and challenge stigma may also be needed in parallel.

Procedure

Ethical approval was obtained from the Department of Psychology and Human Development at IOE, UCL's Faculty of Education and Society. The survey was set up on the Qualtrics online platform, with a link to the survey disseminated through the Cambridge Autism Research Database (CARD).[1] CARD is an established database of autistic adults and parents of autistic people, predominantly based in the United Kingdom, who volunteer to take part in autism research (https://www.autismresearchcentre.net/). Applications to recruit participants via CARD are considered and approved by a scientific committee before studies are advertised in a monthly mailout to their database of volunteers. All participants read the participant information sheet and provided consent before proceeding to the survey. Data collection occurred during November and December 2021.

Participants

A total of 208 participants consented to taking part in the survey, of which 64 did not complete the survey. Participants were told that they could skip any questions and could also withdraw at any point by closing their web browser. Thus, partial responders (i.e. participants who exited the survey before the end point) were excluded from the final sample. Complete responders were defined as those who reached the end of the survey and submitted their responses, even if they had not answered all the questions. A total of 144

Table 1. Participant characteristics.

Participant characteristics	*N* = 144 (100%)[a]
Parent/caregiver of an autistic person	38 (26.39%)
Autistic adult	124 (86.11%)
Formal diagnosis of autism	
Yes	115 (92.74%)
No	8 (6.45%)
Degree of openness about autism diagnosis/identity	
Not open (does not tell anyone)	3 (2.42%)
Selectively open (only tells selected people)	39 (31.45%)
Open (neither hides nor actively tells others)	39 (31.45%)
Very open (actively tells and educate others)	33 (26.61%)
Gender identity	
Man	50 (34.72%)
Woman	75 (52.08%)
Non-binary/other	18 (13.19%)
Age	
18–24	9 (6.25%)
25–34	21 (14.58%)
35–44	30 (20.83%)
45–54	38 (26.39%)
55–64	32 (22.22%)
65–74	14 (9.72%)
Ethnicity	
White-British	116 (80.56%)
Other white background	16 (11.11%)
Asian	4 (2.78%)
Middle Eastern	1 (0.69%)
Mixed background	5 (3.47%)
Other ethnic group (unspecified)	2 (1.39%)

[a] The total number of parents/caregivers of an autistic person and autistic adults exceeds 100% because 18 participants belonged to both categories.

autistic adults and caregivers/parents of autistic individuals living in the United Kingdom completed the survey. Table 1 contains a breakdown of the participants' characteristics.

Data analysis

Table 2 shows the questions included for data analysis. For quantitative data, descriptive summaries of the responses to each multiple-choice question were produced. For qualitative data, thematic patterns were developed from responses across all open-ended questions. This approach followed Braun et al. (2021), who recommend treating qualitative survey data as one cohesive dataset, coding and developing analytic patterns across the entire dataset rather than summarising responses to each question.

We adopted a reflexive approach to thematic analysis (TA), which involved six phases: familiarising with the data, coding the data, generating initial themes, reviewing and developing themes, refining, defining and naming themes, and writing up (Braun & Clarke, 2019). Reflexive TA involves later theme development, whereby themes are developed from codes and conceptualised as patterns of shared meaning underpinned by a central organising concept. This stands in contrast to coding reliability TA, where themes are often developed early based on data collection questions and conceptualised as domains. Coding reliability TA typically requires multiple researchers to use a coding frame to correctly identify evidence falling within each domain, whereas reflexive TA is not about 'accurate' coding but about the researcher's thoughtful engagement with their data. Here, coding is understood as an inherently subjective process that requires a reflexive researcher who strives to reflect on their assumptions and how these might shape their analysis (Braun & Clarke, 2021).

Regarding positionality, the author who led the analysis (EH) does not identify as autistic. All the authors endorse a neurodiversity-affirmative approach to autism research: we believe that there is no one 'correct' way of thinking, learning or behaving, and that divergence from the norm should not be pathologised (e.g. Walker, 2021). We also align with social models of disability (e.g. Oliver, 1986), which explains that autistic people are disabled by societal barriers (which systemically exclude/discriminate against them) and not by within-person impairments or deficits. As the purpose of this survey was to inform the potential development of a stigma support programme, we were more likely to identify data that align with these beliefs. However, EH was particularly conscious of her own beliefs about the need for such a programme, and the importance of remaining open to differing views. The researcher was guided by participatory research values throughout the analysis and write-up process, trying to ensure that autistic voices were genuinely heard and represented.

To enhance the trustworthiness of our analysis, we followed the 15-point checklist of criteria for good thematic analysis by Braun and Clarke (2006). We ensured that our themes were not developed from a few examples but instead from a comprehensive range of examples across the dataset after thorough review and re-review of the data. In addition to selected quotes embedded within our analytic narrative in the Results section, we have collated a longer table of data extracts corresponding to each theme and sub-theme in the supplemental material to demonstrate a good 'fit' between our analytic claims and the raw data. All quotes and extracts are also accompanied by a unique identifier code to show that a variety of participants have been represented. To enhance the quality of our reporting, we applied the 20 questions for evaluating thematic analysis manuscripts by Braun and Clarke (2020). This included clearly specifying which type of TA we used and ensuring that our procedures reflected this form of TA. As explained in the preceding paragraphs, we used

Table 2. Questions used for data analysis.

Question	Analysis
Do you think it is important for autistic adults to have support in managing stigma?	Quantitative
Please explain your answer to the previous question.	Qualitative
Based on the information in the video and table, do you think it would be more suitable to adapt the HOP programme or STORM programme for autistic adults?	Quantitative
Please explain your answer to the previous question.	Qualitative
What thoughts or advice do you have on making the stigma support programme more relevant to and helpful for autistic adults?	Qualitative
What do you think would be the best way of delivering this programme?	Quantitative
If this programme is delivered in small groups of autistic adults, do you think it should be held online or in-person or a mix of the two?	Quantitative
What do you think would help autistic adults to take part in this programme?	Quantitative
What do you think would prevent autistic adults from taking part in this programme?	Quantitative

HOP: Honest Open Proud; STORM: Standing Up For Myself.

reflexive TA rather than coding reliability TA, and as such did not seek to include multiple coders to establish inter-rater reliability; rather, a single researcher led the analysis (in discussion with the other researchers) and strived to reflect on her own positioning.

Community involvement statement

This study was conducted by a team that included both autistic and non-autistic members, who had research and/or lived expertise in relation to autism and/or stigma. Autistic team members were involved in developing the research questions and data collection materials. While they were not directly involved in data analysis, they reviewed and discussed the findings with the first author, which informed the write-up of the paper.

Results

Quantitative results

Most respondents ($n = 114$, 79%) thought it was important for autistic adults to have support in managing stigma, with 52% indicating 'definitely yes' and 27% indicating 'probably yes'. Seventeen percent felt that autistic adults may or may not need support in managing stigma, and the remaining 4% felt that autistic adults would 'probably not' or 'definitely not' need such support. When presented with two stigma-related support programmes designed for individuals with mental health problems (HOP) or intellectual disabilities (STORM), 44% thought that it would be suitable to adapt either programme for autistic adults, 25% thought HOP seemed more suitable, 16% thought STORM seemed more suitable, and 15% felt neither programme would be suitable for autistic adults.

In terms of delivery method, 32% preferred a small group of autistic adults with a trained facilitator, 18% preferred one-to-one with a trained facilitator, and 13% preferred a guided self-help approach (e.g. completing a workbook on their own with the option to contact a trained facilitator). 'Other' responses (37%) commonly stated that the programme should use a combination of these approaches or make all three options available for participants to choose, depending on their needs. If the programme were to be delivered in a small group, 20% preferred it to be conducted online, 22% in-person, and 58% a mixture of the two.

The key facilitators to participation endorsed by respondents were providing clear and detailed information so participants knew what to expect beforehand (83% of respondents), and conducting it online with flexible ways of participating (70%), followed by having a trained facilitator who is autistic (52%) and involving the autistic adult's caregiver/family member (41%). 'Other' potential factors (29%) that could help autistic adults to take part included allowing more processing time, providing visual content, adopting a very logical format and structure, as well as coordinating with existing local adult autism support groups.

The main barriers to participation endorsed by respondents were travelling and sensory environment (77%), uncertainty about what the programme involves (75% of respondents), and not feeling comfortable or ready to talk about their diagnosis (64%). These were followed by not wanting to be in a group with other autistic people (51%), shame or embarrassment (41%), and not needing help to cope with stigma (38%). 'Other' potential factors (32%) that could prevent autistic adults from taking part included not realising that they are experiencing stigma or that stigma is affecting them, not seeing how the programme will help them or change stigma, communication difficulties, emotional difficulties, social anxiety, struggling with group situations, struggling with technology, privacy concerns, time commitment concerns, and pandemic-related safety concerns. Table 3 delineates the quantitative responses given by autistic adults and parents/caregivers.

Table 3. Breakdown of quantitative responses.

Response categories	Autistic adults	Parents/caregivers
Autistic adults' need for stigma support	**124 (100%)**	**38 (100%)**
Definitely yes	64 (51.61%)	23 (60.53%)
Probably yes	34 (27.42%)	6 (15.79%)
Might or might not	21 (16.94%)	6 (15.79%)
Probably not	3 (2.42%)	3 (7.89%)
Definitely not	2 (1.61%)	0 (0.00%)
Suitability of HOP and STORM programmes	**122 (98.39%)**	**38 (100%)**
Both HOP and STORM seem equally suitable	54 (43.55%)	15 (39.47%)
HOP seems more suitable	30 (24.19%)	13 (34.21%)
STORM seems more suitable	19 (15.32%)	4 (10.53%)
Neither HOP nor STORM seem suitable	19 (15.32%)	6 (15.79%)
Preferred format of delivery	**124 (100%)**	**38 (100%)**
Small group	39 (31.45%)	12 (31.58%)
One-to-one	23 (18.55%)	5 (13.16%)
Guided self-help	18 (14.52%)	3 (7.89%)
Other	44 (35.48%)	18 (47.37%)
Preferred mode of delivery	**122 (98.39%)**	**35 (92.11%)**
Online	25 (20.16%)	6 (15.79%)
In-person	25 (20.16%)	8 (21.05%)
Mix of online and in-person	72 (58.06%)	21 (55.26%)
Facilitators to participation	**123 (99.19%)**	**37 (97.37%)**
Providing clear and detailed information beforehand	104 (83.87%)	28 (73.68%)
Conducting it online with flexible ways of participating	91 (73.39%)	23 (60.53%)
Being led by a trained facilitator who is autistic	69 (55.65%)	17 (44.74%)
Involving the autistic adult's carer/family member	44 (35.48%)	25 (65.79%)
Other	37 (29.83%)	9 (23.68%)
Barriers to participation	**123 (99.19%)**	**37 (97.37%)**
Concerns about travelling and sensory environment	96 (77.42%)	26 (68.42%)
Uncertainty about what the programme involves	93 (75.00%)	27 (71.05%)
Not comfortable or ready to talk about their diagnosis	80 (64.51%)	21 (55.25%)
Not wanting to be in a group with other autistic people	63 (50.81%)	22 (57.89%)
Shame or embarrassment	51 (41.13%)	12 (31.58%)
Not needing help to cope with stigma	50 (40.32%)	14 (36.84%)
Other	41 (33.06%)	10 (26.32%)

HOP: Honest Open Proud; STORM: Standing Up For Myself.

Qualitative results

Four main themes were identified in the qualitative data: (1) 'We need to change society not autistic people', (2) 'Stigma is difficult to manage alone', (3) 'Focus on positive, practical support', and (4) 'There is no one size fits all approach'. Figure 1 displays these themes and their subthemes. All quotes below are accompanied by a participant number and code, with 'AA' referring to an autistic adult, 'PC' to a parent/caregiver of an autistic individual, and 'AA-PC' to a participant who identified as both an autistic adult and a parent/caregiver of an autistic individual.

Theme 1: 'We need to change society not autistic people'. Participants emphasised that the problem of stigma lies with society and not autistic people. Therefore, the primary onus should be on non-autistic people to change their attitudes and behaviours, rather than on autistic people to cope with stigma: 'I believe that it is important to be clear that prejudice and ignorance stem from society and individuals not from autistic people–it is not our responsibility to change others, but we can help society to change!' (P122, AA).

Sub-theme: 'Autism is not widely understood'. Participants felt that the general population has little to no understanding of autism: 'I think the real problem is that there is widespread ignorance in the general population about autism and neurodiversity' (P41, AA). They highlighted that most public knowledge about autism appears to be stereotypical, as fostered by media portrayals of autistic people: 'I think the majority of the population [still] thinks that autism looks like "Rainman", so are intolerant and

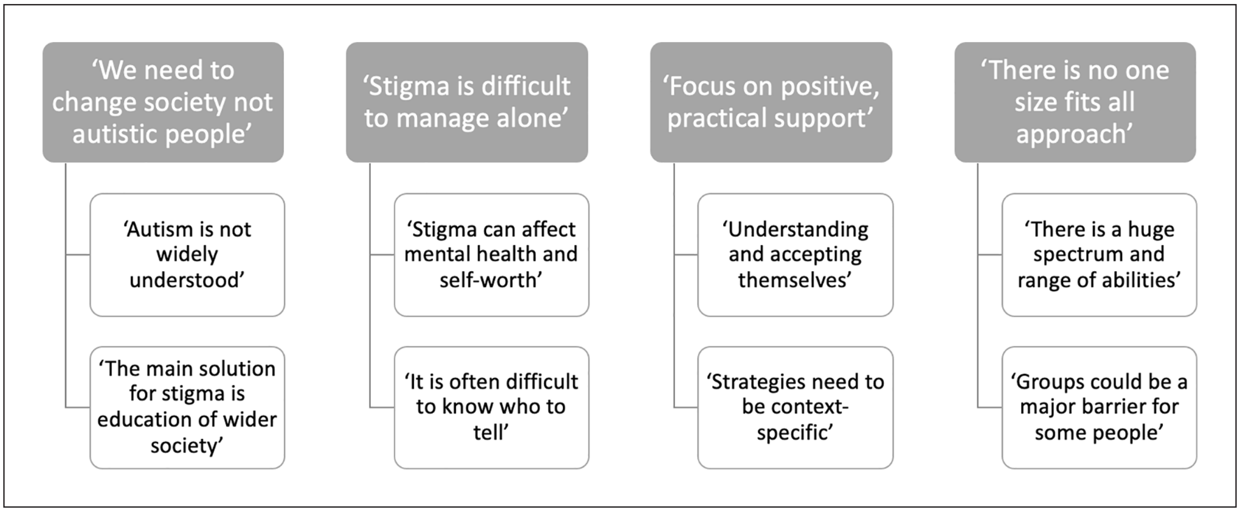

Figure 1. Themes and sub-themes.

sometimes resentful of people [whose] autism [don't] present like "Rainman", which then further alienates and isolates them' (P106, AA). Autistic adults experienced being met with disbelief if they did not fit the stereotypes others had in mind: 'When I disclose my autism very frequently people either think I have learning disabilities or, if they realise that I am quite capable academically and professionally, they dismiss my autism and think I'm lying or have a fake diagnosis' (P126, AA). They described how broad and harmful assumptions regarding their abilities and personalities caused significant problems for them both at work and in their day-to-day life, as others failed to make necessary accommodations or judged them based on their label rather than on merit.

Sub-theme: 'The main solution for stigma is education of wider society'. Given that stigma was perceived to stem from ignorance, participants suggested that the main solution was to increase public awareness and understanding of autism: 'An ideal way to dispel the stigma surrounding autism would be to educate non-autistic people about autism'. (P47, AA). This led some participants to be opposed to the idea of a stigma support programme for autistic people: 'I do not believe that such programmes [should] exist at all. [It] is up to employers, society and everyone to understand and appreciate autism, not for autistic people to [be] told it is normal to expect negative responses when telling people you are autistic' (P92, PC). Meanwhile, other participants felt that both efforts targeting autistic and non-autistic people are needed: 'I think it is important that we support autistic adults to manage stresses and strains of modern society. I also think we should educate people more about autism and learn more about the condition while discouraging discrimination towards autistic people' (P96, AA). A few participants also recognised that it can be empowering for autistic people to educate those around them: 'Involvement in the retraining of society empowers those being ostracised–it gives people a sense of power to elicit change, rather than being powerless. A lot of stigma is about an imbalance of power' (P122, AA).

Theme 2: 'Stigma is difficult to manage alone'. Those who saw value in a stigma support programme for autistic adults reported that stigma is a pervasive reality in many autistic people's lives, and it can be challenging to deal with judgement and negativity on a daily basis on their own: 'I find stigma is difficult to manage alone because when people react in strange ways, I take it wholly on board and it makes me feel really uncomfortable. I also start to see myself through their eyes. I was diagnosed extremely late and I encountered a lot of scepticism from people I thought I could trust with the information' (P100, AA-PC).

Sub-theme: 'Stigma can affect mental health and self-worth'. Participants shared that 'lack of understanding, information and the stigma attached to autism can cause autistic adults to feel ashamed, embarrassed or misinformed about their condition' (P74, AA). They also explained that 'there are various different unhelpful beliefs about autistic people [that] can be damaging to self-worth' (P133, PC), causing low self-esteem, self-doubt and trauma to those who are subjected to it. This was perceived to have an extensive negative psychological impact: 'Stigma is something that can hurt people very much and has long-term consequences for mental health and wellbeing' (P97, AA). Hence, these participants recognised that it was important for autistic people who experience stigma and are affected by stigma to be protected from internalising it: 'It would be good to have an outlet instead of internalising the effects of stigma' (P77, AA). They lamented the general lack of support available for autistic adults, which was felt to breed 'insecurity and confidence issues' (P27, AA). They called for more post-diagnostic support to promote autistic adults' mental health and wellbeing, part of which would include support to deal with the stigma surrounding autism.

Sub-theme: 'It is often difficult to know who to tell'. Another common sub-theme under the difficulty of managing stigma related to disclosure. Autistic adults highlighted the struggle of ascertaining who it was safe to disclose their diagnosis to, and how to go about it in a way that would allow them to avoid bias and discrimination: 'The question is–what do I do as an autistic person–I want to explain how the world looks and feels to me and why I have difficulties with certain environments but, at the same time, I don't want people to see my diagnosis as a negative thing that they have to "deal" with or that is an inconvenience' (P111, AA). Some described facing negative outcomes of disclosure, including judgmental responses, hostility and rejection, which then made them extremely cautious about telling people that they are autistic. Others recognised that internalised stigma prevented them from disclosing, even if others may not necessarily stigmatise them: 'I think I hold a lot of self-stigma around autism, and that motivates me to not tell other people, who may not hold such prejudices' (P140, AA).

Both autistic participants and parents of autistic individuals mentioned that many autistic adults mask (hide their autistic traits, whether by a conscious decision or a behaviour which becomes so ingrained that the person is no longer aware of doing so): 'My adult son with a diagnosis spends most of his time masking in public because of the stigma attached to autism' (P49, AA-PC). Masking was perceived to have additional negative effects on mental health: 'This stigma is reinforced into us as the more that we mask the more people treat us better and so reward us for treating ourselves badly' (P35, AA). Therefore, some participants saw the need for support on how to unmask: 'There is a lot on the Internet of people's experiences of "unmasking", but no one actually helps with this. No one supports you to navigate how people's perceptions of you change, how you change what you think about yourself. There are lots of layers of internalised ableism that prevent people [from] being who they are and feeling better about themselves, but you have to work it all out alone' (P50, AA).

Theme 3: 'Focus on positive, practical support'. In order for support to be beneficial, participants stated that it should be positive and practical, rather than focusing on negative experiences of stigma that may increase feelings of victimisation: 'Stigma is bad and hurtful; I know from experience. However sometimes it is better not to remind people they are victims' (P89, AA). In view of that, a few participants felt that the concept of 'stigma' should be left out altogether, including one caregiver who expressed, 'I wouldn't want to introduce the idea of stigma to my son for whom we try to make autism as positive as possible' (P92, PC). Others, however, felt that it would be helpful for autistic adults to learn how to identify stigma: 'Autistic adults may not recognise stigma when it occurs, as it can be subtle and often conveyed through things other than words' (P143, PC). Nonetheless, there was general consensus that the programme should revolve around empowerment and not 'mutual sympathy'.

Sub-theme: 'Understanding and accepting themselves'. Participants stressed that autistic adults should be equipped with knowledge of their own autism, and that this understanding should be grounded in the neurodiversity paradigm or social model of disability: 'Participants should receive helpful information that challenges the predominant views of autism, especially medicalized views, as well as the disability justice resources'. (P118, AA). Accordingly, autistic adults should be encouraged to see autism as 'positive or neutral, rather than negative' (P110, AA) and 'less of a disability and more of a difference' (P63, AA). Some participants also suggested that the programme should enable autistic adults to identify advantages of autism and how to make use of them or 'sell themselves', which can help to bust myths and stereotypes. Others preferred a balanced approach that would help autistic people to understand and accept both their strengths and limitations: 'I think it is key to educate autistic people on the strengths of their condition and promote confidence in being upfront and honest about any difficulties they anticipate' (P21, PC).

Sub-theme: 'Strategies need to be context specific'. The second aspect of providing positive and practical support pertained to developing context-specific strategies for responding to stigma and/or disclosing one's diagnosis. One autistic adult explained, 'generalised ideas will be too complicated to apply in the moment as you need a great deal of social skill and self-awareness to alter them to each situation' (P23, AA). One parent also stated, 'Discussing the different types of people they might meet is important. For example, they might want/need to behave differently if they are talking to an employer as opposed to police authorities' (P15, PC). The context most commonly mentioned by autistic adults in our sample was employment: 'Perhaps someone is about to apply for a job and [wants] to educate themselves on discrimination law and also to access practical information to support them through the recruitment process e.g. a list of phrases to help them disclose or even challenge something being said in a way that is respectful and appropriate to the context of recruitment' (P134, AA). A few mentioned that they would like to learn scripts and planned behaviour, or suggested that scenarios and role-play could be used to practise the skills taught.

Theme 4: 'There is no one size fits all approach'. A recurring theme throughout the data was that there is no single approach that would be suitable for every autistic individual. Given the heterogeneity of the autistic population, participants acknowledged the difficulty of designing a support programme that would be relevant to all: 'The relevance would need to take into account the continuum that is autism, and be matched to the cohort, which, as we know, varies considerably . . . What is then helpful to one person is patronising to another, and so on' (P76, AA-PC).

Sub-theme: 'There is a huge spectrum and range of abilities'. Participants highlighted the wide range of intellectual abilities among autistic adults and importance of ensuring that support is pitched at the right level: 'not too patronising if it's for autistic adults without intellectual disabilities, but also not too complicated for those with' (P4, AA). They also emphasised the need to accommodate different communicative abilities: 'Non-speakers, who face some of the most severe stigma and are a population whose views are routinely ignore[d], should be actively recruited and not segregated from the speaking groups' (P118, AA). One caregiver expressed that her autistic son would need her support to participate: 'my son would not interact or understand if I were not there' (P83, PC).

Following on from differing abilities, participants recognised that autistic adults may differ in their level of awareness of stigma: 'Some may be unaware of other people's attitudes towards them or towards autism in general. Others may be acutely aware. It would need to be a flexible programme' (P116, AA). They may also vary in their level of confidence in managing stigma: some 'may prefer not to have support in this situation, as they feel that they can manage' (P109, PC). The type and level of support needed could depend on time of diagnosis, with potential differences between autistic people diagnosed as adults versus those diagnosed as children, and individuals who are newly diagnosed versus those who have had a diagnosis for some time. Linked to this are potential disparities in prior knowledge of autism and involvement in the autism community: 'Some people will have read a lot about autism, have already done a lot of self-discovery, or be heavily involved in communities, so might be in a better position to reflect than those who are perhaps still adjusting to seeing themselves as/admitting to themselves that they are autistic' (P108, AA).

Sub-theme: 'Groups could be a major barrier for some people'. Many autistic adults mentioned that they would not personally attend a group programme: 'group sessions . . . would dis-incentivise me from taking part and hinder my learning–taking turns, filtering out the noise of other voices and presenting our own thoughts are problems most autistic people experience' (P136, AA). In particular, they felt that discussing sensitive topics such as identity and stigma would be anxiety-inducing in a group setting: 'discussing something as deeply personal as how I feel about being autistic in the presence of a group, and not knowing what people are thinking, would be too stressful' (P81, AA). Some proposed that one-to-one support would be more appropriate: 'individual support mixed with informative videos explaining about what autism [is] and how as an autistic adult the individual has very positive things to give to the community they live in would be more helpful' (P98, AA). Others preferred a self-help guide they could complete in their own private space and time: 'I would go through an online workbook or PowerPoint as I'd be able to remain anonymous' (P134, AA).

However, a few participants felt that 'it would be helpful to hear the experience of others' (P46, AA) and 'one of the key benefits might be enjoying time spent in the company of other autistic people face-to-face, regardless of learning about disclosure strategies' (P139, AA). To make a group format work, they recommended keeping group sizes small and group members as similar to each other as possible. Many mentioned that allowing virtual attendance would make the programme more accessible: 'The way you could do this is through Zoom [and other video communication platforms]. Everyone has their cameras and mics off, no one has to interact at all, but they can turn on their mics and cameras if they like. They get to actively choose their role in the group this way, making it less intimidating to autistic people (P74, AA)'.

Discussion

Using a mixed methods survey, we examined the views of autistic adults and parents/caregivers of autistic people on whether a stigma support programme for autistic adults is needed and what it should 'look' like. Quantitative data showed that most participants felt it was important for autistic adults to have support in managing stigma. Qualitative data revealed some of the reasons behind this, including the negative impact of stigma on mental health and the challenges that autistic people face in navigating disclosure. However, concerns were also raised that such a programme would be placing the burden on autistic people to cope with stigma rather than on society to remove stigma. For support to be beneficial, respondents suggested that it should have a positive and practical focus on building self-understanding and self-acceptance, as well as developing context-specific strategies for responding to stigma and/or disclosing one's diagnosis. Regarding programme delivery, both quantitative and qualitative data revealed diverse preferences and underscored the importance of flexibility (i.e. offering different ways of participating and taking into account a wide range of needs).

First, it is crucial to consider the valid concerns raised by participants that such a programme could convey the message that stigma is a normal and acceptable part of being autistic. It should be noted that such comments were not only made by those who were against the idea of a stigma support programme, but also by those who were in favour of or unsure about such a programme. In other words, some participants felt that programmes to manage stigma could be helpful, but that programmes to reduce stigma towards autistic people were more important. Some participants also emphasised that it is not autistic people who need to change, but support can empower autistic people to educate others and elicit change in society. Meanwhile, a minority stated that such support should not exist at all, and that society needs to educate itself. These sentiments are perhaps unsurprising given the persistent onus placed on autistic individuals to change and 'fit in', with many interventions being designed to reduce atypical behaviours and/or teach normative behaviours without clear benefits for the autistic individual (Bottema-Beutel et al., 2018; Mottron, 2017). For years, the autistic self-advocacy and neurodiversity movements have opposed these attempts to 'cure' or 'normalise' autistic people, instead calling for more interventions that can improve mental health and quality of life for the autistic population (Leadbitter et al., 2021; Pellicano et al., 2014). We echo these sentiments.

Our findings have important implications for how stigma-related interventions for autistic people are framed. Compared to an intervention that focuses directly on stigma (like STORM), an intervention that empowers individuals to make strategic disclosure decisions (like HOP) may be more acceptable and relevant to the autistic community. It is noteworthy that many respondents brought up issues of disclosure even before HOP was presented in the survey, including how public and internalised stigma led to concealing or masking, which in turn reinforced stigma. Such experiences have also been well-documented in previous research (Punshon et al., 2009; Schneid & Raz, 2020) and points to how a disclosure-focused programme like HOP could be useful to autistic adults in several ways. For those who decide to disclose, HOP may reduce the risk of internalised stigma by promoting positive group identification, community pride and active engagement in advocating for social change (Corrigan et al., 2013). By supporting effective disclosure (i.e. sharing the right information with the right person at the right time), HOP also has the potential to indirectly reduce public stigma via positive contact experiences, although this has not been empirically tested. For those who decide not to disclose, HOP may still be beneficial by ensuring that non-disclosure is empowered and not driven by internalised stigma or shame (Scior et al., 2020). Regardless of the individual's decision(s), support in the decision-making process can help to increase self-efficacy in managing stigma and decrease stigma-related stress. Nonetheless, it should be made clear that stigma is a societal and systemic problem, and that interventions targeting those who are stigmatised only represent a small part of the much wider efforts needed to address stigma at multiple levels. Relatedly, such interventions should be developed and evaluated with the goal of contributing towards broader support for the mental health and wellbeing of autistic people, alongside other programmes that have been created to help them understand and accept their diagnosis.

Our findings also highlight several considerations regarding how stigma-related interventions for autistic adults are delivered. It was apparent from the qualitative data that a group approach would be helpful for some, but challenging to the point of being inaccessible for others. While a group format was preferred by about a third of participants in the quantitative data, about half of participants also endorsed 'not wanting to be in a group with other autistic people' as a potential intervention barrier. Dissociation from the stigmatised group may be indicative of internalised stigma, and it is arguably these individuals who need a stigma support programme the most. Other research has shown that autistic adults can benefit from being in a group with other autistic people, including gaining a sense of belonging, feeling less socially isolated, meeting positive role models and learning from each other's experiences (Crane, Hearst, et al., 2021; Crompton et al., 2020; Leedham et al., 2020). However, autistic adults who are struggling with internalised stigma and disclosure may be less likely to attend a group programme. Recruitment in past HOP studies has been difficult for the same reason, which led to the recent adaptation of HOP in a guided self-help format combined with an optional online peer forum (Scior et al., 2021). Further research would be needed to determine whether a similar format combining both individual and group options (as our participants suggested) may be feasible and acceptable to autistic adults, and we have reported our plans to test an autism-specific version of HOP elsewhere (Han et al., 2022). Existing studies do indicate that online forums may be particularly well-suited for autistic people (albeit not all), as they can accommodate different modes of communication, alleviate sensory concerns, and provide a safe space for autistic individuals to explore and express a positive collective identity (Brownlow & O'Dell, 2006; Parsloe, 2015).

A major limitation of our study was the lack of attention paid to intersectionality, a term coined by Crenshaw (1989) to describe how people with multiple stigmatised identities experience compounded forms of discrimination. According to Crenshaw, understanding differences within stigmatised groups is needed to effectively engage in collective action that transforms a stigmatised identity into an empowered one (Crenshaw, 1991, as described in Botha & Gillespie-Lynch, 2022). In relation to disclosure, intersectionality also introduces additional layers of complications, as autistic people may not only be concerned about disclosing their autistic identity but also other stigmatised identities, and the concealability of these identities may also vary. However, our sample was predominantly White, and we did not collect extensive demographic information (e.g. on sexuality, socio-economic status, or co-occurring disabilities) that would give us insights into intersectionality. Autistic people from racial, ethnic, gender, sexual minorities and/or low-income backgrounds are typically underserved and underrepresented in autism research and practice (Steinbrenner et al., 2022; Strang et al., 2020). Moving forward, it is crucial that stigma-related research and support for autistic people appreciate and account for their multifaceted identities, ensuring that such efforts do not ignore or even reproduce other forms of stigmatisation. In addition to the lack of ethnic diversity, it should be noted that as we only recruited participants from one database, our sample may not be representative of the larger autism community in the United Kingdom (an issue that we have expanded on in a footnote within the Methods section). Nonetheless, it was encouraging to see that our survey garnered rich and nuanced data from participants with varying degrees of openness about their autism diagnosis/identity, across different age groups, and with diverse opinions on the proposed programme.

Although our sample comprised many more autistic adults than parents/caregivers, we do not perceive this as a limitation as we believe that autistic voices should be centred in research and development of support that directly concerns them. At the same time, including input from parents/caregivers provided additional, valuable perspectives. For example, there were a few parents who commented that they were participating precisely because their autistic grown-up child was conscious of stigma and reluctant to identify as autistic. However, it must be acknowledged that there may be disparities between the views of autistic adults and parents/caregivers, especially those who are not autistic themselves. The quantitative data suggest that autistic adults and parents/caregivers may value different things in an intervention, as autistic adults were more likely to endorse having a trained autistic facilitator, while parents/caregivers were more likely to endorse caregiver involvement. In the qualitative data, parents' comments that stigma-support programmes should not exist may also stem from a more idealistic position that is possible because they are not the main targets of stigma. Moreover, parents' reluctance to introduce the concept of stigma to their children align with research on autism diagnosis showing that non-autistic parents may withhold information from their autistic child to protect them from stigma, while autistic parents may prefer honest discussions that facilitate better self-understanding and stronger autistic identification (Crane, Lui, Davies, & Pellicano, 2021; Smith et al., 2018). This links to intersectionality, as parents from racial and ethnic minorities tend to prepare their children for stigma and impart community pride, whereas parents of autistic individuals who do not share the same minority identity may respond to stigma differently (Botha & Gillespie-Lynch, 2022). Nonetheless, as there were a few autistic adults/autistic parents who also expressed a more idealistic or protective stance (e.g. 'autistic people aren't the ones who need this', 'leave out the word stigma'), these differences are not conclusive.

To conclude, we gathered insights from the autism community on whether stigma-related support is needed for autistic adults and if so, what it should 'look' like. Our results suggest that it may be worthwhile to pursue interventions that focus on empowerment, self-acceptance and disclosure strategies within a multi-level framework of stigma reduction efforts. However, intervention researchers and practitioners need to be extremely careful that they do not inadvertently reinforce stigma by suggesting that stigma is the fault of the individual, or that internalised stigma is a flaw that needs correcting (Corrigan & Rao, 2012). While this is applicable to interventions that target the stigmatised individual generally, its importance here cannot be overstated given the deficit narrative that has characterised much autism intervention research (see Leadbitter et al., 2021 for a discussion). In trying to help autistic people mitigate the negative effects of stigma, researchers and practitioners must continue to engage in participatory practices, critically reflect on their positions and privileges, and seek to redress the power differences that underpin stigma.

Data accessibility

Ethical approval and participant consent were not obtained for raw data sharing. Due to the confidential and sensitive nature of our data, there is no data that can be disclosed beyond that contained within the manuscript and supplemental material.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

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Supplemental material

Supplemental material for this article is available online.

Note

1. Note that we had originally intended to recruit participants via a broad range of routes, to maximise the diversity of the sample. However, recruitment via the CARD alone yielded our target of a large sample (i.e. over 100) with diversity in the degree of openness about their autism diagnosis/identity (which provided the richness required to enable us to address our key research questions). It should be noted, however, that the Autism Research Centre (ARC) at Cambridge University was recently the subject of unprecedented controversy, linked to the launch of a genome-wide association study, Spectrum 10k. There have been many serious concerns raised by the autistic community and their allies regarding this project, which centre around a 'lack of transparency in recruitment and engagement, consent issues, the suitability of the principal and co-investigators, and the possibility that the data and results could be used towards eugenics' (Natri, 2021, p.2). Following public calls to boycott ARC research, the representativeness of the ARC's database is questionable. Importantly, however, the resulting database did provide the diversity in responses we were seeking, including those with seemingly high levels of internalised stigma.

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