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THE DEVELOPMENT OF A STIGMA SUPPORT INTERVENTION TO IMPROVE THE MENTAL HEALTH OF FAMILY CARERS OF AUTISTIC CHILDREN

Suggestions from the Autism Community**

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Parents and family carers of autistic children report poorer mental health than any other parents. Stigma surrounding autism plays a significant role in the mental health of family carers of autistic children, often leaving families feeling isolated. Yet there are currently no interventions available to support families with stigma. In order to guide the design and development of an intervention to improve the psychological well-being of parents and carers of autistic children by addressing the stigma they may experience, we surveyed the autism community (n = 112) about their views and suggestions to make such intervention more successful. The thematic analysis of the qualitative responses revealed that respondents wished for public awareness to be raised and suggested that education would be the key to this. Respondents also – recommended that parental self-esteem and self-compassion skills should be increased and that they would benefit from ‘ready-made’ phrases or information available to react to instances of stigma from the public, other family members, and professionals. The autism community provided valuable suggestions to be incorporated in the design of a stigma support intervention for parents of autistic children, in order to improve their mental health and caregiving abilities.

Keywords: parental mental health, stigma, autism, intervention, support

1. Introduction

Autism is a neurodevelopmental condition characterised by diagnostic professionals as impacting upon social interactions, verbal and nonverbal communications, and engendering a narrow spectrum of interests and behaviours (APA 2013). Estimates

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of autism's prevalence have increased dramatically over the last 30 years and the latest (and only) prevalence study of autism suggests that 1.1% of the UK population may have autism (BRUGHA 2012), which is in line with studies from Asia, Europe, and North America, where an average prevalence between 1% and 2% is reported (CHRISTENSEN et al. 2016).

Parents or family carers of autistic children (i.e. anyone providing unpaid, full-time care for an autistic child) report higher levels of anxiety and stress, as well as a lower psychological well-being than the general population (BENSON & KARLOF 2009) and compared to parents of children with other disabilities (BAKER et al. 2011; HAYES & WATSON 2012). A key issue linked to the risk of poor mental health among parents or carers is the stigma associated with autism, which has been reported to be highly prominent in the lives of such families (SCHALL 2000; NTSWANE & VAN RHYN 2007; DIVAN et al. 2012; HARANDI & FISHBACH 2016; KINNEAR et al. 2016). ALI and colleagues' (2012) systematic review of 20 studies reporting data on stigma and the well-being of family carers of children with intellectual disabilities (including studies sampling autistic children) found consistent evidence that stigma affects parents' psychological well-being and increases the risk of parental stress and caregiver burden. Autism stigma has also been linked with the risk of developing depression (DABABNAH & PARISH 2013; CRABTREE 2017), anxiety (GREY 2002; CHAN & LAM 2017) and psychological distress (WONG et al. 2016) among family carers. Negative reactions and attitudes from others, including the idea that parents or carers should be blamed for their child's 'atypical' behaviour (NEELY-BARNES et al. 2011; ROBINSON et al. 2015) also lead families to feel socially isolated (WOODGATE et al. 2008) and socially excluded (KINNEAR et al. 2016), which is likely to compound poor mental health and self-esteem, and undermine confidence in their parenting abilities (CRABTREE 2007; NEELY-BARNES et al. 2011; DABABNAH & PARISH 2013).

Furthermore, interviews with parents of autistic children in studies from CASHIN (2004) and WOODGATE and colleagues (2008) demonstrated how parents of autistic children can experience changes to their sense of self and their identity. The internalisation and application of prejudicial attitudes to oneself, or self-stigma, exacerbates negative emotional responses and behaviours (CORRIGAN & WATSON 2002) such as reduced self-esteem, reduced hope and self-efficacy, reduced quality of life and social avoidance (LIVINGSTON & BOYD 2010; PAPADOPOULOS et al. 2018).

Given the link between stigma and mental health, it is reasonable to expect that through supporting parents and family carers in coping with stigma, a positive impact on mental health should be observed. Given JELLET and colleagues' (2015) findings that parental mental health difficulties and child behavioural problems of young children on the spectrum are interlinked, interventions that improve parental mental health and wellbeing should also result in improving the child's wellbeing and quality of life. However, the development of interventions that support the mental health of parents or family carers of autistic children is in its infancy. Further, to our knowledge, currently no interventions are available that specifically address the stigma that these families experience.

Various stigma reduction interventions have aimed to reduce stigma on the intrapersonal, interpersonal, and societal level. HEIJNDERS and VAN DER MEIJ (2006) reviewed stigma reduction strategies and interventions at various levels in the fields of HIV/AIDS, mental illness, leprosy, TB and epilepsy, and argue that interventions should aim first at empowering affected persons. Intrapersonal stigma interventions are designed to empower the affected individual to cope with the stigma they experience by changing characteristics such as knowledge, attitudes, and behaviours. The development of such interventions remains a relatively new area of research. Self-stigma interventions are in their infancy and stigma interventions for caregivers are rare. There are currently no completed interventions available that help parents of autistic children cope with the stigma they experience or provide them with skills to protect them against internalising experienced stigma.

For the development of such intervention, it is important to include the views of the autism community, which in this context refers to autistic people, their family members, and the professionals who support them. According to Bos and colleagues (2013), many stigma interventions lack thorough theory and methodology. Bos and colleagues (2013) propose that the design stage of such interventions should be in collaboration with the target population and relevant stakeholders. An important limitation in current autism research and practice is also the lack of involvement of the autism community, in particular for intervention research (PELLICANO et al. 2014). Understanding the views and needs of the target population should enable interventions to be developed in a way that is most appropriate and engaging (NHS 2008). The UK's Medical Research Council guidelines for the development of complex interventions also highlight the need to address the view of key stakeholders in the development of interventions (CRAIG et al. 2008). PELLICANO and colleagues (2014) also argue that the involvement of the autism community should be 'genuine and not tokenistic' (p2). In line with this ethos, we aimed to engage in a listening exercise with the autism community in order to elicit their views and perspectives that could inform the design and development of a planned stigma-focused intervention for parents and family carers of autistic children.

2. Methods

2.1. Procedure and participants

An online survey consisting of quantitative and qualitative questions was constructed using the secured online survey software 'Qualtrics' (www.qualtrics.com) to explore the autism community's experiences of stigma and views on a planned stigma intervention, titled 'Stigma of Living as an Autism Carer: A Brief Psycho-Social Support Intervention (SOLACE)' (LODDER et al. 2017). Anyone aged over 18 years and identifying with the autism community was eligible to participate during the period 15th December 2016 to 30th June 2017 when data collection occurred.

A link to the survey was distributed to 670 members of the Autism Spectrum Database UK (ASD-UK). ASD-UK is a UK research family database of children

with an autism spectrum disorder funded by Autistica and conducted at Newcastle University. The survey was also promoted through social media including via Twitter and via the Facebook Group ‘London Autism Group’, which had 800 members at the time. This post was also shared publicly on the authors’ personal accounts. A total of 198 individuals completed the full survey with 112 respondents providing data pertaining to their views of our planned intervention. The majority of respondents were parents of a child with ASD (93%) and female (89%). A full breakdown of the participants’ background characteristics can be found in *Table 1*. Ethical approval was granted by the Institute of Health Research Ethics Committee at the University of Bedfordshire (ref: IHREC702). Approval was also secured from the ASD-UK Research Committee. Online informed consent was obtained from all individual participants included in the study.

Table 1
Participant characteristics

<i>Participant characteristics</i>	<i>N = 112 (100%) *</i>
<i>Parent</i>	N = 104 (92.9%)
<i>Autistic Individual</i>	N = 19 (17.0%)
<i>Autism Professional</i>	N = 16 (14.3%)
<i>Friend of autistic individual</i>	N = 9 (8.0%)
<i>Gender</i>	N = 112
<i>Female</i>	N = 100 (89%)
<i>Male</i>	N = 11 (9.8%)
<i>Transgender</i>	N = 1 (0.9%)
<i>Age (range 21–63 years)</i>	Mean 42.24 (SD = 8.5)
<i>Relationship Status</i>	N = 112
<i>Married</i>	N = 68 (60.7%)
<i>Single</i>	N = 21 (18.8%)
<i>Divorced/Widowed</i>	N = 10 (8.9%)
<i>Co-habiting</i>	N = 8 (7.1%)
<i>Not disclosed</i>	N = 5 (4.5%)
<i>Religious Affiliation</i>	N = 105
<i>None</i>	N = 48 (45.7%)
<i>Christian Protestant</i>	N = 33 (31.4%)
<i>Catholic</i>	N = 14 (13.3%)
<i>Muslim</i>	N = 2 (1.9%)
<i>Buddhist</i>	N = 2 (1.9%)
<i>Spiritual</i>	N = 2 (1.9%)
<i>Greek Orthodox</i>	N = 1 (1%)
<i>Jewish</i>	N = 1 (1%)
<i>Pagan</i>	N = 1 (1%)

<i>Importance of religion affiliation (0–10 with 10 being very important)</i>	Mean 3.2 (SD = 3.1)
<i>Ethnicity</i>	N = 111
<i>White British</i>	N = 80 (72.1%)
<i>White</i>	N = 26 (23.4%)
<i>Chinese</i>	N = 2 (1.8%)
<i>Pakistani</i>	N = 1 (0.9%)
<i>Somali</i>	N = 1 (0.9%)
<i>Mixed race</i>	N = 1 (0.9%)
<i>Education</i>	N = 112
<i>Doctorate Level</i>	N = 4 (3.6%)
<i>Masters/ Post graduate</i>	N = 14 (12.5%)
<i>Bsc University degree</i>	N = 33 (29.5%)
<i>Post graduate diploma</i>	N = 20 (17.9%)
<i>College/NVQ</i>	N = 18 (16.1%)
<i>A-levels</i>	N = 8 (7.1%)
<i>GSCE/high school</i>	N = 14 (12.5%)
<i>Dropped out of school at 15</i>	N = 1 (0.9%)
<i>Employment</i>	N = 112
<i>Full time</i>	N = 38 (33.9%)
<i>Part-time</i>	N = 16 (14.3%)
<i>Self employed</i>	N = 12 (10.7%)
<i>Unemployed</i>	N = 13 (11.6%)
<i>Carer to child/home maker</i>	N = 24 (21.4%)
<i>Student</i>	N = 2 (1.9%)
<i>Retired</i>	N = 2 (1.9%)
<i>Volunteer</i>	N = 2 (1.9%)
<i>n/a</i>	N = 3 (2.7%)
<i>Perceived Financial Situation</i>	N = 112
<i>Excellent</i>	N = 6 (5.4%)
<i>Good</i>	N = 43 (38.4%)
<i>Fair</i>	N = 41 (36.6%)
<i>Poor</i>	N = 22 (19.6%)

* The total exceeds 100% because a number of participants are not only parents but also autistic individuals (n = 9) or autism professionals or friends of autistic individuals.

2.2. Data collection tool

The survey included an information sheet detailing the aims of the survey: to take the views of the autism community on board in the design of an intervention aiming to support parents and carers of autistic children with the stigma they experience. A brief description of the planned intervention was given as well as open-ended questions asking about stigma experiences, the impact this had upon their well-being, and a question that elicited their views and suggestions for a stigma support intervention. This paper focuses on the responses to the question ‘What advice/thoughts/views do you have about making our planned caregiver stigma intervention more likely to be effective, feasible, practical, acceptable and/or sensitive?’ Responses to the question ‘Do you have any other views about what future research studies investigating the stigma towards autism should focus upon?’ were reviewed too for responses related to a planned stigma intervention.

2.3. Analysis

The written responses were read repeatedly and analysed thematically (BRAUN & CLARKE 2006). Using Nvivo 11.0, codes were assigned to the responses by the first author. In some cases, a phrase could fit into more than one theme. If a response could not be easily coded, the first two authors discussed the response until agreement was reached about appropriate code(s). After all coding was completed, the transcripts were reviewed again by both authors to ensure that the categories covered all vital aspects of the responses and any disagreements were discussed until consensus was reached.

3. Findings

The analysis of the responses revealed five themes, which are presented in *Table 2*.

Table 2
Overarching themes with sub-themes

<i>Main category</i>	<i>Sub theme</i>
<i>Education & Awareness</i>	Education of general public (n = 27)
	Education of professionals (n = 13)
	Education for parents of autistic children (n = 7)
	‘Ready-made information’ (n = 6)
<i>Boosting self-esteem & resilience</i>	Boost self-esteem (n = 13)
	Develop thick skin (n = 5)
<i>Compassion</i>	Self-compassion (n = 11)
	Compassion for others (n = 8)
	Empathy & Recognition (n = 7)

Intervention format & design

Group structure (n = 12)

Involved autism community (n = 6)

Timing of intervention (n = 5)

Barriers to attendance (n = 4)

Free sharing time (n = 3)

Focus on fathers (n = 1)

Autism diagnosis

Focus on positives of autism (n = 9)

Being open about diagnosis (n = 7)

Autism is heterogeneous (n = 6)

3.1. Education & Awareness

Many respondents referred to raising awareness and education to reduce stigma. Respondents provided suggestions to target stigma at a society level and offered detailed accounts on why they think stigma occurs, the negative impact it has upon them, and the view that a lack of understanding from the public contributes to stigma:

‘There has to be more awareness about what autism is, the extent of the spectrum and associated behaviours. The public need to be educated, for example regarding the challenging behaviours of High Functioning ASD children, who may present themselves as “normal” in every other way so that their parents are not accused for poor parenting skills’ (53-year-old mother of an autistic individual).

Respondents made suggestions for the education of the public (or ‘others’), professionals, and parents, leading to three subthemes: 1) education of the general public, 2) education of professionals, 3) education of parents.

3.1.1. Education of the general public

Respondents suggested that the education of the public through targeted campaigns should see a reduction in stigma. Responses varied from stating that the public should be educated (*‘The wider community needs to be educated with regards to autism’*, 36-year-old mother of autistic child) through to personal experiences of educating the public (*‘I always take the opportunity to educate now rather than getting angry’*, 50-year-old mother of autistic individual) through to their wish for more awareness (*‘I would like more public awareness of what is taking place when a child has a meltdown so that they will not make nasty comments or judge parents trying to cope with difficult situations’*, 39-year-old mother of autistic son)

Some respondents gave rather brief answers (e.g. *‘education and awareness’*) but some responses provided a deeper insight into why respondents may have offered suggestions for strategies to reduce public stigma rather than suggestions for an intervention aiming to help caregivers cope with stigma or protect against stigma:

'I am not sure how this kind of intervention will help as it is the attitude of others and a lack of public knowledge about autism that is the problem' (40-year-old mother of two autistic sons). And *'I don't know people are always going to judge what they don't understand or experience themselves'* (47-year-old mother of three autistic sons).

3.1.2. Education of professionals

Respondents expressed feeling stigmatised by professionals and stated that education and more awareness from professionals would reduce stigma. Caregivers described how professionals do not acknowledge the difficulty the parents may go through, for example: *'We are sometimes seen as pushy parents/caregivers, we are not, we are just tired and exhausted from all the effort we put in to help our children'* (42-year-old mother of an autistic child) or how professionals may not acknowledge the diagnosis as one parent points out: *'So many people, including healthcare professionals, would try to convince you that it is not autism, when it is, and you know it'* (43-year-old mother of an autistic child).

'I think all professionals should on a regular basis be trained on ASD. In my experience most people have been on a day course and this is acceptable, it's not especially those that work with children closely, e.g. teachers, doctors. In my experience, they are the ones who seem to have no patience or time. Regular updated training annually should be given to all professionals working with children and adults' (42-year-old mother of three autistic children).

'Packs for teachers or workshops for school peers for those who are in mainstream schools. Children can be cruel at what they do not understand. Also, it would be beneficial for teachers to have yearly updates and made (not offered) to go to seminars where they can learn from parents – not from a book' (38-year-old mother of autistic child).

3.1.3. Education of parents

Some respondents also voiced the need for the education of caregivers (*'Some information on the different presentations of autism, especially PDA as it does not seem to be very well understood by professionals, let alone caregivers'*, 36-year-old mother of an autistic child). Respondents mentioned that education or support should be more clearly signposted as many seem uncertain about the available support. One participant, for instance, noted: *'You need to advertise more that support for people on the autistic spectrum exists and that supporters of those people can access training. People don't know there is help out there they can access'* (40-year-old female, friend of an autistic individual).

Another participant suggests that a national pack which details help available, lists local support groups, and describes common feelings that parents may be exposed to, would be very useful. One respondent suggested that educating care-

givers to recognise stigma by providing examples of stigma would be useful for an intervention.

3.1.4. 'Ready-made answers'

Respondents provided further practical suggestions on how to help families be protected from autism stigma including the suggestion of providing families readily available information:

'Giving families information in a shareable and accessible form, so that ignorance in others is reduced, therefore reducing stigma, and increasing understanding' (49-year-old mother of an autistic child). They also explained how having 'key phrases' ready when faced with ignorant or negative attitudes from others, helps them deal with stigmatising situations and how this could empower others (and thus be used in an intervention):

'Give ideas of how to respond to negative comments - planned responses for the type of comments that frequently come up would empower the caregiver' (43-year-old mother of an autistic child).

'I have learnt a few key phrases, so even if caught off guard I can respond' (36-year-old mother of an autistic son).

3.2. Self-esteem

Respondents suggested that the intervention should aim to boost parents' self-esteem, including their confidence in their parenting style:

'Give them self-esteem, god knows any parent needs it, but I can't help feeling that those who parent ASD children need it even more. Give them confidence to call people out on their lack of knowledge and judgments, and give them the understanding that it is going to be ok. ASD changes, the child develops and what seems like the end of the world today may not seem like it in a few months' (39-year-old mother of autistic child).

Caregivers also suggested that improving self-esteem may help with the lack of recognition from professionals: *'I think it is important to be strong and have a clear focus in mind - so many people, including healthcare professionals, would try to convince you that it is not autism, when it is, and you know it'* (43-year-old mother of autistic child).

3.2.1. Developing a 'thick skin'

Other respondents suggested that caregivers build up their self-esteem by developing resilience to negative views from others, including the idea of developing a 'thick skin'. This phrase was used to describe their experience as well as a way to suggest for others to deal with the stigma they may encounter. For example: *'My personal feelings from my own experiences are that caregivers should just grow thicker skins'* (47-year-old mother of three autistic children).

‘Having two autistic children has opened my eyes about how judgmental my environment is. One needs to develop a thick skin to cope with every day life but that’s not always easy. Other people’s behaviour can be very hurtful and very often we feel excluded’ (35-year-old mother of two autistic children).

3.3. Compassion

Respondents provided suggestions to be more compassionate towards oneself and also expressed the view that taking a more forgiving view towards the public’s lack of awareness and negative attitudes, helps coping with the experienced stigma.

3.3.1. Self-compassion

Respondents pointed out that being kind to oneself and being accepting of oneself provides a positive way to deal with stigma: *‘None of this is your fault. Even on a bad day, you are a good parent’* (45-year-old mother of an autistic child).

Respondents suggested that caregivers should not feel ashamed of their children and suggest the use of mindfulness to prevent getting anxious about stigmatising situations.

‘. . . One good way is to teach them Mindfulness. So you can learn to focus the mind on the here and now rather than getting anxious about what may be about to happen or what has just happened’ (50-year-old autistic mother of an autistic child).

Respondents also stressed the importance of self-compassion by taking some respite from the stress of caring for an autistic child. Others asked for the intervention to provide techniques to manage stress in order to be able to cope with the challenges of meltdowns and other challenges associated with raising an autistic child. Others added that caregivers should not accept the judgements of others as true, and find their own positives to build from. For example:

‘They [. . .] need to understand that people may judge them but that does not mean they should accept the judgement as true. They need to learn to find their own positives and develop these’ (41-year-old mother of an autistic child).

3.3.2. Compassion for others

Some respondents viewed the public with compassion, too, and applied this perception as a positive coping mechanism. These respondents acknowledged that the public’s reaction towards an autistic individual is the result of a lack of awareness and/or understanding. One respondent, for example, states:

‘Be careful to differentiate between stigma and misunderstanding. Much about Autism is still not known to the general public and it’s important to know when someone is judging based on the Autism vs something said in ignorance’ (23-year-old autistic male).

Another respondent shared this view noting that *'You may feel everybody looks at you in a negative way but this may not actually be the case'* (42-year-old mother of an autistic child). This mother suggested possibly using cognitive behaviour therapy strategies as a means of re-evaluating negative experiences.

Others expressed how they choose to ignore the public but understand that it is the public's ignorance that is causing their negative attitudes: *'I don't tend to react to these people, as you will just come across angry and out of control, there is no changing these people's minds'* (43-year old mother of an autistic son).

'Don't feel ashamed of your children, it could happen to the people who are being ignorant. Don't hide away, society won't recognise the challenges of ASD if we hide away' (40-year-old mother of an autistic child).

3.3.3. Empathy & Recognition

Participants noted that they do not feel they are taken seriously or have received empathy and understanding from others, and in particular from health professionals. Participants stated that there is not enough recognition from professionals that parents can be knowledgeable about their child's needs and behaviour and expressed a desire to be taken more seriously.

'Showing what living with autism is like daily, how much a caregiver has to fight to get relevant procedures put in place in school, nursery etc. The effort a caregiver has to put in when a child is in mainstream to ensure the person with autism has a chance to learn. We are sometimes seen as pushy parents/caregivers, we are not, we are just tired and exhausted from all the effort we put in to help our children' (42-year-old mother of autistic child).

3.4. Intervention format & design

A quarter of responses related to practical suggestions for the intervention such as the format or its mode of delivery. Respondents suggested group sessions, free discussion time to share experiences during the sessions, and an online platform to talk to each other in between sessions.

'Would suggest offering an easily accessible venue e.g. Children's Centre... Group sessions with parents/carers. Add online support forum so they can share ideas between sessions. Allow time for them to share concerns and what helps. Usual caveats about confidentiality' (47-year-old autistic female).

3.4.1. Group structure

Respondents expressed the need and desire for caregivers to realise they are not alone and to share experiences with others who understand what they are going through. *'I think it is important for carers to know that they are not alone even though they may feel despair at times'* (58-year-old mother of an autistic boy).

'That there is the understanding there and that other parents/families with similar needs will be there and they can all help each other' (38-year-old mother of an autistic child).

It was also argued that meeting other caregivers or parents should not substitute other support for their child or interventions to help their child's behaviour. As one caregiver commented: *'It helped me to know other parents with autistic children; however I didn't like it when "parenting support groups" were offered to me as an alternative to real support for my child'* (41-year-old mother of autistic child).

3.4.2. Barriers to attendance

It seems parents want to meet others in a similar situation but are also overwhelmed by the challenge that raising an autistic child brings, and the time it would take to commit to attending sessions. One respondent mentioned that ten weeks would be too much of a time commitment and asked for a *'short, sharp and effective'* intervention program. Others pointed out that childcare would be a barrier for attending sessions (daughter of an autistic mother and mother of an autistic child, 37).

3.4.3. Timing of intervention

Respondents voiced the need for early intervention and one asked for it to be available before diagnosis. One parent explains how caregivers may need more support for stigma when the diagnosis has first been made because caregivers may be more reactive to people's negative or careless comments at that time. This parent explains that:

'I think you need more support for things like stigma when you first get the diagnosis – as you are in shock, you worry about your child and their future, and you kind of mourn the future you don't even know that they won't have yet! You are much more reactive to people's negative or careless comments. As you move along the years, it is easier, and you come more to terms with the condition, that it is not the end of the world, and that anyone who judges you or your child, simply lacks the intellect to see beyond their own set of life circumstances.'

Other suggestions, that were related to the delivery format of the intervention, referred to the facilitator of such intervention. Two parents commented that the facilitator should have a thorough understanding of autism and should use evidence-based research to deliver the intervention.

3.4.5. Involve the autism community

Several respondents expressed the need for the autism community to be involved in research, practice, and delivery of an intervention. *'It would be best to plan with parents / caregivers who have been through it as they may have advice, information that you may not think about'* (30-year-old mother of autistic child).

‘... Work with the individual and taking notice of what their needs are and what they say they are! The biggest expert about their behaviour and needs is them!’ (63-year-old female tutor for autistic children). One caregiver commented that there should be particular attention paid to fathers as they are often an overlooked group.

3.5. Autism diagnosis

Respondents expressed the importance of understanding that autism is heterogeneous and that interventions should cater for the whole spectrum, not just for caregivers of ‘high functioning’ autistic children. Some argued the importance of understanding autism as a matter of difference, rather than something that is ‘wrong’, and that there should be a focus on autism’s positives:

‘I would focus on the positives of the condition. Particularly reminding that the people with ASD are different – and not wrong. I always tell my son that if someone judges him poorly just because he has autism, then they are the idiot, as they don’t really know why they don’t like him, his difference seems to single him out to be judged harshly at times. I always remind him of the talents he has and the positives of his condition, rather than the negatives’ (43-year-old mother of an autistic son).

3.5.1. Being open about the diagnosis

Some respondents recommended that caregivers should learn to be open to others about the diagnosis as this has helped them reduce stress and resist stigma.

‘We have been as open as possible with friends / teachers / parents of children that attend my son’s nursery about the possibility of our son’s autism. We have found that this has reduced some of our stress levels and people in general have been very supportive’ (37-year-old father of a boy currently undergoing autism diagnosis).

‘I feel that it is important to tell people about our child’s disability, autism is a non-physical disability so it is difficult for people to see it in society, but I find being honest with people can very often defuse situations that arise’ (42-year-old mother of an autistic boy).

Respondents also commented that they feel it is important to be open about the diagnosis to the autistic individual so that they understand it and are therefore better equipped to deal with stigma.

‘It is important that kids with ASD are told about their condition in a secure and positive way, so that they don’t think there is something wrong with them – we were lucky with our son – we told him everyone was special, but he was just a bit more special, and that normal didn’t exist as every person is different, we showed him lots of amazing people with autism – and after that things were better – it is harder when people are unkind when the child doesn’t know’ (43-year-old mother of an autistic son).

However, one mother commented how she rather not disclose the diagnosis: *‘... as a parent you are always worried about meltdowns, and you feel it’s nobody’s*

business that they know your child had autism; as he gets older, it's his choice to tell people' (48-year-old mother of an autistic child).

4. Discussion

The main suggestion from the autism community was raising awareness and educating others about autism. Many respondents provided suggestions to target stigma at the societal level and offered detailed accounts of why they think stigma occurs, particularly the view that a lack of understanding from the public results in stigma. Respondents showed a strong desire for professionals to be better educated about the differences in autism and felt that a lack of knowledge and understanding from professionals contribute to stresses and challenges in their lives. Carers thought professionals do not receive enough autism training and suggested that refresher courses should be mandatory. They also argued for schools to help in raising awareness and that teachers should have more knowledge and understanding. These responses do not provide a direct suggestion for the design of an intervention at the intrapersonal level. However, they do illustrate how concerned the autism community is in relation to misunderstandings and misconceptions, and how carers feel they struggle with stigma in various contexts.

Respondents described educating others as a means towards coping with stigma. This is in line with findings from HARANDI & FISHBACH (2016) who carried out a survey to explore how parents of children with ASD dealt with stigma. They found that parents used proactive strategies to educate the public about autism; for example, carrying cards with information about autism. A recent study by AUSTIN and colleagues (2017) compared mothers' disclosure strategies and found that carrying cards was a more successful method to protect against stigma than compared to wearing a wristband or no disclosure. Similarly, the respondents from the current study suggested having 'ready-made' information, such as information packs or a leaflet to hand out when needed. Respondents also suggested having 'ready-made' verbal responses to be able to respond quickly to negative or ignorant comments from the public or other family members who do not understand or accept the autism diagnosis. With a stigma support intervention design in mind, participants working together to produce such ready-made information (for example, in the form of cards) could be a valuable and beneficial exercise to help parents/carers feel empowered and more confident to cope with negative attitudes from the general public, other family members, and/or professionals.

Respondents suggested educating family carers to achieve a better understanding of the complex world of autism. Psychoeducation is a commonly used method to reduce self-stigma in other populations. According to CORRIGAN & WATSON (2002), people are at risk of internalising stigma when they agree with the stereotypes that are held about them and apply these to themselves; thus, boosting the parents' knowledge may lead to a rejection of the public's stigmatising views and, crucially, might prevent the internalisation of such stigma. Psychoeducation may also help empower caregivers (THOMAS et al. 2015) and improve self-esteem, both of which moderate

the relationship between stigma and psychological well-being (KNIGHT et al. 2006). Participants in the current study also recommended boosting carers' self-esteem as a means to cope with public stigma, including negative interactions with professionals.

There was also support for the idea of connecting with other parents/carers and sharing their experiences with others in the same situation. This desire from parents to connect with others is consistent with the literature. KERR and MCINTOSH's (2000) study found that contact with other parents of children with similar disabilities provided emotional, social, and practical support that could not be derived from professionals or family and friends. Higher levels of social support are associated with lower levels of depression (BENSON 2012), stress, caregiver burden (KHANNA et al. 2011) and higher levels of emotional and physical health (EKAS et al. 2010; SAWYER et al. 2010; KHANNA et al. 2011).

Group membership and identification may play an important role in moderating people's reaction to stigma (TAJFEL & TURNER 1979). A strong identification with the group may reduce the risk of self-stigma by reducing stereotype agreement and self-concurrence, and strengthening self-esteem (YANOS et al. 2010). Group identification may also provide a basis for giving, receiving, and benefiting from peer social support, in turn increasing the resistance to stigma and the rejection of negative in-group stereotypes (TURNER et al. 1994). A sense of belonging is also likely to reduce social isolation, the latter being another important moderator of the stigma and mental health relationship (MAK & KWOK 2010). A group-based intervention with group activity should facilitate this and aligns with this study's findings.

A recent development in the autism stigma literature is the role of self-compassion as a protective factor in the stigma-mental health relationship. CHAN and LAM (2017) discovered that parents who have higher levels of self-compassion are less affected by stigma than parents with lower levels of self-compassion. The ideas of being more compassionate and less judgmental of oneself were identified in the current study. Self-compassion in parenting means circumventing self-blame and, as suggested by DUNCAN and colleagues (2009), it may also reduce the social evaluative threat that parents may feel when perceiving judgements by others, especially when their child's behaviour is perceived to deviate from the social norm. One way to increase self-compassion is through the principles of acceptance commitment therapy (HAYES 2002), for example, through developing an accepting relationship with one's internal experience. Acceptance-based approaches may be particularly effective and suitable for family carers of children with autism as they can be brief in nature and are relatively easy to implement. Indeed, the view that an intervention with less of a time commitment would be more feasible to implement is consistent with the findings drawn from this study. Face-to-face interventions include challenges such as time commitment, travel, and childcare issues (WHITEBIRD et al. 2011), all of which were identified by the current study's respondents. This suggests that a 'blended intervention', where face-to-face meetings are supplemented with online support, may be the most practical and beneficial approach for this population (LIPMAN et al. 2011; CLIFFORD & MINNES 2013).

Another interesting finding was the belief that having a more compassionate and forgiving view of those who stigmatise may make judgments and/or negative comments from the public less hurtful. This is because some respondents felt that negative attitudes may not necessarily be the public's 'fault' and that misunderstanding is not the same as mistreatment. Using cognitive restructuring techniques to change automatic thought patterns about negative attitudes from others may help prevent the internalisation of stigma (LUCKSTED et al. 2011).

5. Limitations

This study utilised a modest sample size of which most participants were females, mothers of children with autism, white, highly educated, and UK-based. Moreover, participants were self-selected, and it could be argued that participants with stronger views or who endured more negative experiences of stigma were disproportionately more likely to participate.

Numerous participants provided suggestions for the education of others, as opposed to suggestions on how to cope with stigma at the intrapersonal level. This may mean that some participants misunderstood the purpose of the intervention; for example, believing that the intervention's focus was on 'those who stigmatise' rather than 'those being stigmatised'. Alternatively, it may signify that respondents felt stigma to be so ingrained in society and so much a part of life that they could not see the hope in an intrapersonal-based intervention. This uncertainty reflects the key limitation associated with such online surveys; that we are unable to fully ascertain and further explore the meanings behind given responses.

Despite these limitations, we were able to collect a wide breadth of respondents, many of whose responses were very detailed, and which provided some powerful suggestions to be taken into account for the design and development of an intervention at the intrapersonal level.

6. Conclusion

This study is the first of its kind to explore the views of the autism community on an intervention helping caregivers cope with the stigma they may experience. Valuable suggestions were made which should be taken into account when developing a stigma protection intervention, such as increasing self-esteem and self-compassion and parent-to-parent support. Based on these findings and those from the literature, an intervention could aim to challenge autism myths and stereotypes through psycho-education; develop skills how to recognise and cope with stigma to prevent internalising stigma; increase self-compassion; increase self-esteem; increase social support and reduce social isolation through group discussions and the sharing of experiences whilst highlighting the positives of autism and taking into account the heterogeneous nature of autism.

7. Compliance with Ethical Standards

Ethical Statement: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest: The authors declare that they have no conflict of interest.

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