

ORIGINAL ARTICLE

‘Standing up for Myself’ (STORM): Development and qualitative evaluation of a psychosocial group intervention designed to increase the capacity of people with intellectual disabilities to manage and resist stigma

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Abstract

Background: People with intellectual disabilities are at risk of experiencing stigma and require the skills and confidence to deal with stigma in their daily lives.

Method: Development and piloting of a 5-session manualised psychosocial group intervention designed to increase the capacity of people with intellectual disabilities aged 16+ to manage and resist stigma. Ten pre-existing groups ($N = 67$) in third sector and education settings participated. Interviews with participants ($n = 26$), facilitators ($n = 9$) and significant others ($n = 7$) 2–4 months after the intervention assessed perceived impact.

Results: Perceived benefits of the intervention for participants included increased understanding, improved connections with others, drive for advocacy, increased activity and self-efficacy, and opportunity to process difficult events and emotions. Differential impact depending on individuals' pre-existing self-advocacy skills was noted.

Conclusions: This early-stage study indicates that further evaluation is merited to examine feasibility and outcomes of the STORM intervention.

KEYWORDS

attitudes, intellectual disability, intervention, self-advocacy, stigma

1 | INTRODUCTION

Stigma occurs within contexts of differential power and refers to the co-occurrence of negative stereotyping and prejudice (endorsement

of negative stereotypes), which places those affected at risk of status loss and discrimination (Link & Phelan, 2001; Pescosolido & Martin, 2015). Intellectual disability is an attribute that is generally devalued and those carrying this attribute are often stereotyped as

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'childlike' and 'lacking potential to change' (Gilmore et al., 2003; McCaughey & Strohmer, 2005). Despite many positive changes in policies, service provision and societal views, stigmatising attitudes and discrimination continue to be a reality for many people with intellectual disabilities and contribute to substantial inequalities they experience in their everyday lives, and within health and social care systems (Ali et al., 2008; Emerson et al., 2011). Intellectual disability stigma can also manifest as exclusion and rejection and drive verbal insults, bullying and disability hate crimes (Richardson et al., 2016). Many people with intellectual disabilities are aware of the stigma associated with the label (Beart et al., 2005; Logeswaran et al., 2019). Stigma renders individuals with intellectual disabilities more vulnerable to a negative sense of self and low self-esteem (Jahoda et al., 2010; Logeswaran et al., 2019; Paterson et al., 2012), and self-stigma (attributing negative societal views to oneself) appears to be associated with increased depression and anxiety (Ali et al., 2015). Given the negative impact of carrying a stigmatised label and the exposure to stigma experienced by this population in their everyday lives, developing effective ways to increase their capacity to manage and resist stigma is a priority.

Interventions have been developed in other fields to reduce the negative effects of stigma on sense of self, for example, for individuals with serious mental health problems (Fung et al., 2011; Luckstead et al., 2011) and substance misuse (Luoma et al., 2008). These interventions engage stigmatised individuals as potential agents of change and encourage them to question and distance themselves from negative stereotypes, and seek to bolster their capacity to manage and resist stigma. Stigma management involves protective efforts to enable the stigmatised person to manage and cope with others' negative attitudes and behaviours. Stigma resistance goes beyond avoiding stigma to more actively countering it at personal, peer and/or public levels and has been linked, for example, with improved recovery outcomes in people with serious mental health problems (Firmin et al., 2017). To date, no evaluations have been published of interventions that explicitly aim to enhance the capacity of people with intellectual disabilities to resist stigma (Werner & Scior, 2016). A survey of facilitators of existing groups for people with intellectual disabilities ($N = 40$) across a range of sectors, conducted during the early stages of the current project, indicated the need for such an intervention. Group facilitators noted that others' negative attitudes and behaviours were of concern to many of their members but that discussions about them, and their negative impact on group members, usually happened on an ad hoc basis, if at all; the majority said that a ready-made intervention that could facilitate group discussions on these issues would be very useful.

The main aims of the current study were to develop and pilot a manualised psychosocial group intervention focused on stigma management and resistance that would be suitable for delivery as a public health intervention in a range of settings. This small-scale study is a component within the early stages of developing a new complex intervention (Craig et al., 2008). The issues examined in this paper are: (a) recruitment and retention of participants in the intervention; and (b) intervention impact as perceived by participants, facilitators and significant others at interview.

2 | METHODS

2.1 | Design

Following development of the intervention, an uncontrolled pilot study was conducted using mixed methods to assess recruitment, retention and subjective impact of the 'Standing up for Myself' (STORM) intervention. This paper presents information about the intervention development, recruitment and retention rates, and findings from the qualitative evaluation only.

2.2 | Intervention development

Development of the intervention was overseen by a steering group of researchers, clinicians, self-advocates with intellectual disabilities, and experienced group facilitators (including authors 2–7). The group met in person four times during the 12-month project, and communicated, and shared documents via email between meetings. The research team facilitated feedback between the steering group and a separate self-advocates group (of five members). The programme theory was initially informed by the literature in the intellectual disability field and anti-stigma approaches with other stigmatised groups, the responses from the aforementioned group facilitators' survey, and the steering group and self-advocate's knowledge and experience relating to intellectual disability stigma. These are reflected in the considerations detailed in the logic model (Figure 1) which informed the design of the intervention. Iterative development of the content and format of the intervention manual and resources was undertaken by the research team in close discussion with the steering group and meetings with self-advocates, recognising that co-design with intended users maximises the fit and acceptability of an intervention, as well as its likely effectiveness (Wight et al., 2015). The Standing up for Myself (STORM) intervention draws on cognitive behavioural therapy (Beck, 1978; e.g., examining the benefits and disadvantages of different ways of responding to stigma); narrative therapy (White & Epston, 1990; e.g., by separating oneself from a problematised label and developing new stories about oneself); and liberation psychology (Martín-Baró, 1994; acknowledging acts of oppression).

Peer support throughout the STORM intervention was seen as crucial with hypothesised benefits for wellbeing, sense of self-worth, and responses to stigma (Pistrang et al., 2008; Puschner, 2018). STORM is a manualised intervention, comprising four, weekly 90-min sessions with different key messages addressed in each session, with a fifth follow-up session approximately 4 weeks after the fourth session. The first three sessions use video based first-hand testimonials by people with intellectual disabilities as stimuli for group discussions, with questions and prompts guided by the manual. The fourth session focuses on action planning, with the aim of supporting group members to plan one action they would like to take following completion of STORM and, importantly, to convey the message that everyone can take action and assert one's rights. The follow-up session reviews participants' action plans and problem solves any barriers in working

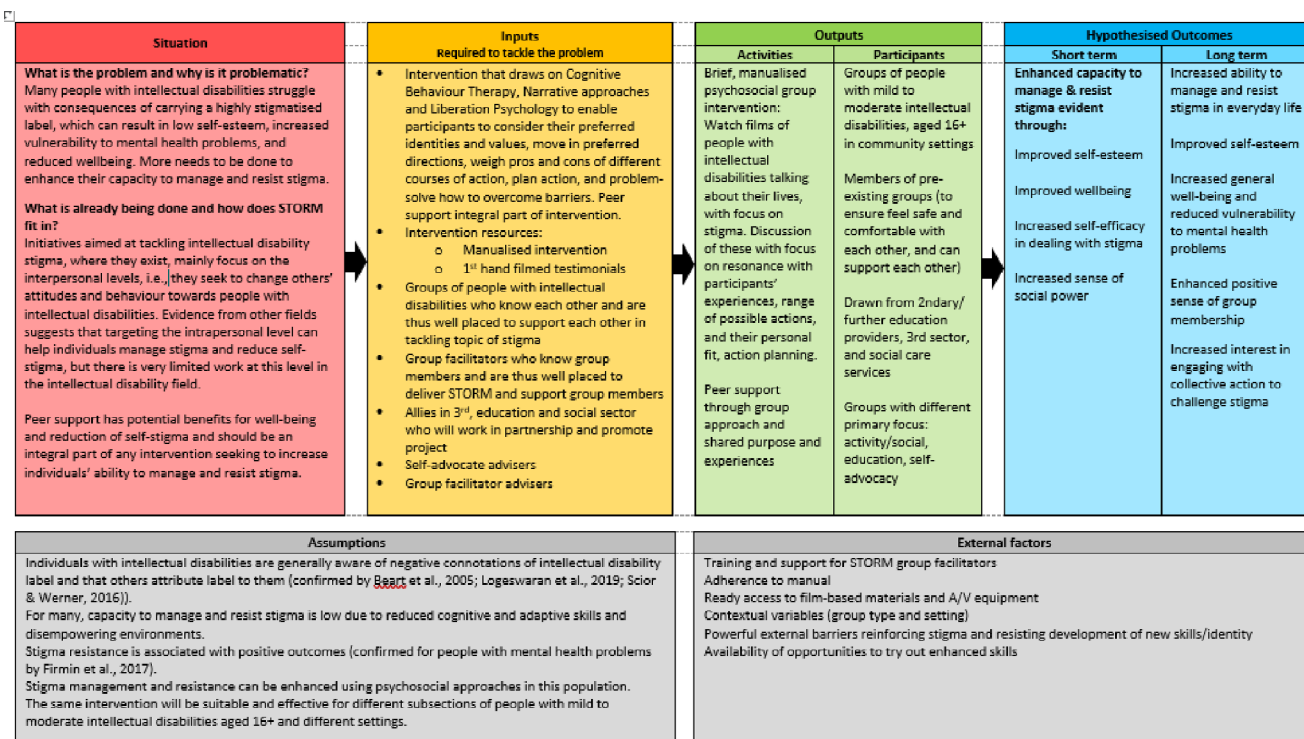


FIGURE 1 Logic model for the STORM programme

FIGURE 2 Summary of STORM key messages and activities

STORM Key Messages	STORM activities
Session 1 <i>My learning disability* is only one part of me.</i>	Videos (4 clips) followed by discussion to explore- - what learning disability means to different people with learning disabilities - what learning disability means to the participants - different parts of participants identity- achievements, hobbies and what they are proud of
Session 2 <i>It's not ok for people to treat me badly. I don't have to put up with it.</i>	Videos (3-4 clips) followed by discussion to explore- - the range of attitudes and actions experienced by people with learning disabilities from people without learning disabilities - participants' own personal experiences of being treated positively or negatively by others
Session 3 <i>I can stand up for myself when people treat me badly.</i>	Videos (3-4 clips) followed by discussion to explore- - strategies that we use to deal with negative attitudes and actions from others - other ways to respond to negative attitudes and actions
Session 4 <i>I can make a plan to help me stand up for myself. People I can trust can help me with ideas.</i>	Begin action planning- - review strategies that can be used to cope with or respond to negative treatment by others and discuss which one(s) suit each group member - make an individual action plan to try over next few weeks Celebration event.
Follow-up <i>Things can get in the way of my plan. Talking to others can help me decide what to do next and not give up.</i>	To review and discuss- - action plans and how they went - ways to manage any barriers that arose

*The STORM intervention uses the term 'learning disability' as this is the most widely used term in the UK to refer to intellectual disability

towards these. A summary of the five sessions, their key messages and resources is shown in Figure 2. STORM is aimed at existing groups (with a social, activity, and/or self-advocacy focus) run for people with intellectual disabilities by facilitators who know the group members and have experience of facilitating. The decision to offer the intervention to pre-existing groups was made as it was deemed familiarity between group members and facilitators would help provide peer support and a safe and containing environment for participants to explore potentially upsetting experiences. Furthermore, working with pre-existing groups meant that a brief intervention could be delivered without the need for additional time for group formation.

The facilitator's manual provides an overview of the intervention and underpinning approaches, guidance for delivering the intervention, and session-by-session plans including things to prepare ahead of each session, activity descriptions, links to videos, and discussion prompts. Optional resources such as posters with key messages, and note pages for group members are also included. Facilitators were provided with the manual and access to a film explaining the rationale for STORM and providing an overview of the intervention. In addition, they were assigned a named member of the research team who met with them to provide more detailed guidance, talk through the session guides, explain the resources and answer questions. This member of the research team was also present at the first session to offer support, if required, and was available during delivery of the intervention for queries and support. Facilitators were not expected to have any formal training or qualification. Designing STORM as an intervention that could be delivered widely and with ease of access was intentional and in line with its intended remit as a public health intervention.

2.3 | Participants

The inclusion criteria for the research were that participants were part of an established group for people with intellectual disabilities that met regularly, were over 16 years of age, and had communication and cognitive skills in line with a mild to moderate intellectual disability, as the intervention was language and discussion-based. They had to be able to give informed consent to participation in the study. No formal assessment of intellectual disability was undertaken, rather an administrative approach to establishing this was employed, through an existing diagnosis and/or use of service for people with intellectual disabilities. Communication and cognitive skills of group members were ascertained through initial screening discussions with the facilitators—the tasks involved were described in detail and sample materials shared to check that potential participants would be able to engage with these. In total, 67 people with intellectual disabilities across 10 groups participated in the STORM pilot, see Table 1. Of the 10 groups, six were third sector run self-advocacy groups, three activity-based groups run in day services, and one a college-based group. Twenty-six group members (10 women, 13 men and 3 gender missing), took part in follow-up interviews. They were recruited from all 10 groups on a first to express interest basis, with two to three members on average interviewed from each group. In addition, nine group facilitators and seven significant

TABLE 1 STORM pilot participants' sociodemographic characteristics ($N = 67$)

	<i>n</i> (%)
Gender	
Female	28 (41.8)
Male	34 (50.7)
Missing	5 (7.5)
Age	
16–24	16 (23.9)
25–34	16 (23.9)
35–44	13 (19.4)
45–54	10 (14.9)
55+	7 (10.4)
Missing	5 (7.5)
Ethnicity	
White British	51 (76.2)
Black British/African/Caribbean/Black Other	7 (10.4)
Asian British/Asian Other	4 (6.0)
Other	1 (1.5)
Missing	4 (6.0)
Education	
Special educational school	43 (64.2)
Mainstream	10 (14.9)
Both	7 (10.4)
Missing	7 (10.4)
Accommodation	
Living with parents or other relative/s	36 (53.7)
Independent	10 (14.9)
Supported living	7 (10.4)
Other	4 (6.0)
Missing	10 (14.9)

others (family members and support workers) of group members were interviewed. By combining group member reports with those of group facilitators, and significant others (who know the group members in a personal capacity), it was hoped to obtain rich feedback on the intervention and its perceived impact.

2.4 | Procedure

Recruitment to the intervention pilot occurred between May and August 2017 via three routes: facilitators who had previously completed a survey conducted by the research team were contacted; the study was advertised at a large charity event; and emails were sent to organisations run for and by people with intellectual disabilities, and to schools and colleges for students with special educational needs. In total, information about the study was shared with 115 groups/local organisations.

Information about the intervention was initially conveyed via group facilitators who were provided with Easyread information to share with their group. If group members expressed interest, a researcher visited the group to go through the information sheet and obtain written consent. Group members were informed at this point that they would be asked to consider participating in follow-up interviews at a later stage.

2.5 | Qualitative interviews

Following completion of STORM, facilitators were asked to invite group members to participate in a 1-to-1 interview (with the second author), with a recruitment target of at least two members per group. All group members who agreed to be interviewed ($N = 26$, 2–3 from each of the 10 groups) took part in a face-to-face interview at the base of each respective group. All available group facilitators ($n = 9$) were interviewed face to face. In addition, group members were asked at their interviews whether they could identify a significant other who they were happy to be contacted for a possible interview, resulting in interviews with seven significant others (five parents and two support workers). Interviews with two significant others took place face to face at their preference, the others via telephone.

All interviews took place four to 7 months after recruitment into the pilot, approximately 2–4 months after the respective group's final STORM session. All were conducted on an individual basis, apart from one instance where two members of the same group requested to be interviewed together. Three separate semi-structured interview schedules were developed with input from the project stakeholders, one for group members, one for group facilitators, and one for significant others. These asked about group members' recollections of the intervention, both to cue them into the interview and to check what they did remember about the intervention, and participants' and facilitators' experiences of the intervention and its perceived impact (positive and negative). Significant others were asked about any impact of the intervention, which they had observed. All interviews were audio recorded with interviewees' consent.

2.6 | Analysis

Interview recordings were transcribed and analysed using thematic analysis (Braun & Clarke, 2004). This approach was selected because the research questions concerned participants' experiences of the intervention and its perceived impact, which fits with thematic analysis' critical realist approach. Coding was undertaken using NVivo Version 12. Ideas that were repeated and appeared significant were labelled and combined to form themes. The analysis was undertaken by the second author in close discussion with the first author.

A hierarchy of overarching themes and their constituent higher order and sub-themes was developed. Themes were reviewed against the transcripts until no new ones were identified. This process was repeated by an independent researcher and any differences and similarities in the themes were discussed and collaboratively refined.

2.7 | Ethical considerations

Ethical approval was obtained from the first author's institutional ethics committee (Project ID 0241/003). Information about the study was initially conveyed via group facilitators who were sent information in an Easyread format to share with their group. If the group expressed interest, a researcher visited the group to go through the information sheet with potential participants before they decided whether to take part and provided written consent. Informed consent was also obtained before audio-recording the interviews. For young people aged 16 and 17, parents were informed about the project in advance in line with usual local procedures.

3 | RESULTS

3.1 | Recruitment to the intervention and retention

Ten established groups (six self-advocacy groups, three day-service groups, and one college-based group) with a total of 68 group members (38 men and 30 women, 4–10 members per group) were recruited over a 4-month period. Recruitment ceased after 10 groups had been recruited in keeping with the study's resources; 15 further groups expressed interest in participating but could not be accommodated.

All 10 groups completed all of the five STORM sessions. One participant dropped out before starting the intervention. Of the 67 participants who started the intervention, 56 (83.6%) attended at least three of the five sessions.

3.2 | Qualitative analysis

The qualitative analysis presents findings regarding group members' recollections of the intervention and the perceived impact of the intervention on group members. Themes are presented in Table 2 and are summarised below and illustrated with verbatim quotes, labelled with GM for group members, F for facilitators and SO for significant others, followed by a label for the type of group: SA for self-advocacy, DS for day service and C for college.

3.2.1 | Recollections of the intervention

All group members interviewed recalled some specific tasks or activities completed as part of the intervention. The most frequently recalled element was the use of videos to highlight key messages and ideas, and involvement in group discussions:

We were watching the DVD. The bloke went on the bus, he was a bit nervous going on the bus and then they were picking on him. Then he didn't go out, he was staying indoors, he was a bit nervous going out.

— (GM, DS).

TABLE 2 Summary of themes

Overarching themes	Higher order themes	Subthemes
1. Group members' recollections of the intervention		
Task based memories	a. Videos b. Group discussions c. Action plans	i. Intellectual disability ii. Bullying iii. Response to maltreatment
2. Impact of intervention on group members		
2.1 Developed understanding and insight	a. Improved understanding of intellectual (and other) disabilities b. Awareness of the treatment of people with intellectual disabilities	i. Challenging myths and stereotypes i. Signs of bullying
2.2 Improved connection with others	a. Strengthened within-group connections b. Increased confidence in social situations	i. Shared experience ii. Increased contribution to group
2.3 Drive for advocacy	a. Enhanced self-advocacy b. Increased standing up for others	i. Involvement in (self) advocacy initiatives ii. Refined skills in self-advocacy iii. Empowerment
2.4 Increased activity and self-efficacy	a. Increased self-efficacy b. Raised independence	
2.5 Processing difficult events and emotions	a. Exploring past experiences b. Reduced self-blame	
2.6 Differential impact	a. High levels of pre-existing self-advocacy b. Some negative impact	

We were talking about feelings, you know, about how people perceive bullying. You know, on the High Street and all that, you know, how people accept people with a learning disability.

— (GM, SA)

Most group members recalled discussing various responses available to them in instances of maltreatment, with some talking about standing up for themselves as one option, while others recalled discussions about calling on support:

We talked about how to stick up for ourselves, like say if someone said something to you, not in a very good way.... We spoke about how we could talk to someone about it.

— (GM, SA)

of the first STORM session to explore what an intellectual disability is and what it means for group members:

I'd say I have more of an understanding about learning disabilities and how it affects people.

— (GM, C)

This in turn allowed the groups to explore myths and challenge inaccurate and unhelpful stereotypes:

The group had a lot of myths around Downs Syndrome, even though they've got members with Downs Syndrome in their group. We could challenge some of those.

— (F, SA)

Insight into the treatment of people with intellectual disabilities developed (closely linked to session 2's key message); experiences recounted in the videos were similar to many group members' experiences and promoted a shared understanding:

I think looking at the videos, at what other people have been through, and how it affects them, you realise you're not the only one in that situation sometimes. ...[I'm] just better at looking out for the signs of people bullying and getting bullied.

— (GM, SA)

3.2.2 | Subjective impact of the intervention

Six overarching themes were identified in relation to the impact of the STORM intervention on group members, see Table 2. These are summarised below.

Developing understanding and insight refers to an improved understanding of intellectual and other disabilities, which relates to the aim

This greater awareness of shared experiences was also noted by group facilitators:

I think for a lot of them it's like "it just happens to me, no one cares about me" and then they see, well it's not just you. Not to diminish what they're going through but to see it as a wider, it's a very big problem.... It's like so now you know it's not just you, you know there are other people you can speak to who will understand what you're going through.

— (F, SA)

Improved connection with others

Group members and facilitators observed strengthened within-group connections and increased contributions to the group:

You can empathise as well, because you are in the same situation, more or less.

— (GM, SA)

When I first come here I was quiet, but now I got to know them and that's it. I talk more.

— (GM, SA)

Increased confidence and engagement in social situations beyond the group setting were reported for some:

He's sort of come out of himself a bit more. I think in all probability he's actually taking a bit more of the lead. He's also in a drama group and he seems to be coming to the front of that more. And I think, although he was beginning to do that, I think probably it was almost as if this group said to him "it's alright to go there and enjoy yourself and be yourself.

— (SO, SA)

Drive for advocacy

An overarching theme was an increased drive of group members to advocate for their own and others' needs following the intervention:

I absolutely love the STORM group so much because I think it's good to get your voice out, as in speaking up for yourself. You've got to stand up and be firm for yourself.

— (GM, SA)

This enhanced self-advocacy was evident in several groups implementing new initiatives, to allow group members to raise public understanding of abuse of people with intellectual disabilities and equal rights. Some of these included materials taken directly from the STORM intervention, whilst others appeared to be underpinned by the ideas of the intervention:

What we're doing now is going into schools to tell them that we actually get bullied and all that. I feel good about that. [We tell them] they shouldn't bully us, take the mickey [tease/ridicule].

— (GM, DS)

The group started their action plan. They've followed through with their poster [about disability rights]. That'll be going up in about 10 different places...local colleges, library, job centre.

— (F, SA)

Participation in the intervention allowed group members to consider and practice ways of standing up for themselves in an effective and assertive manner, and in this sense it was felt they had refined skills in self-advocacy:

STORM made me more confident just by feeling like you're alright, there's nothing stopping you, provided you do it in the right way. You can't go off and swear at them, but if you do it in the right way and the right manner there's nothing wrong with standing up for yourself.

— (GM, SA)

Skill development in this area was also highlighted by some significant others. One mother highlighted a recent situation in which her son had taken active steps to identify appropriate people to support him in standing up for himself, rather than relying on her to address the issue:

We did have a situation at work where he felt that he had been bullied by one of the other staff members and he did actually go to another member of staff and say "this man is not being nice to me". And that was all looked into and they've dealt with it which has been good. So he was able to make his case and not just sit there and take it. He wouldn't have been assertive like that before.

— (SO, SA)

Some group members also reported a shift in their sense of confidence and perceived ability to change others' attitudes and behaviour through their advocacy efforts. This increased sense of empowerment was also noted by facilitators and significant others:

It makes me feel that we can change something if you stand up for yourself. Hopefully some authorities might listen.

— (GM, SA)

Group members also reported increased empathy and greater consideration for others, and a greater willingness to stand up for peers, which was also observed by facilitators:

I learnt to be considerate to others. Listen to what others say.

— (GM, SA)

When we go out as a group I always look out more... I always make sure when I'm out with them I do what I need to do. Like if they need to wait in a queue, I make sure they don't get pushed out. I've took that forward, and I have a couple times said to people "actually you need to wait behind these people.

— (GM, SA)

They're speaking up for their peers as well, which has been really good to see.

— (F, SA)

Increased activity and self-efficacy

Many interviewees highlighted increased engagement in other activities and achievements following the intervention:

I've just done a 3-week course [NVQ], just recently finished, and I passed it, [...] I honestly do think it [STORM intervention] has helped, because with the STORM project I think I gained more experience, because I was low in confidence, I sort of re-built up my confidence by doing STORM and then moved onto doing something completely hard. I didn't think I'd ever pass. But I managed to pass, through STORM.

— (GM, SA)

This appeared to be underpinned by a sense of greater self-efficacy, agency and independence:

I don't have to go ask my mum when I want to go somewhere. I do things by myself better now.

— (GM, DS)

Processing difficult events and emotions

Some group members and facilitators reported that the intervention had allowed the exploration of past events that had previously not been discussed or fully addressed:

It got everybody to talk and we talked about some quite in-depth stuff. Some people started saying some stuff from school.

— (GM, SA)

Others noted that the intervention had reduced self-blame surrounding past negative treatment:

I think it helped me to move on. I think because I learnt it wasn't my fault I was bullied, and I think that's what I'd been thinking, because it's how I am, but I've realised it

wasn't. And because I've been doing this it's taught me "ok, people are mean to people, but it's not your fault, it's them, it's not you. I think I've learnt that doing this, doing STORM.

— (GM, C)

Differential impact

Some group members and facilitators observed that the impact of the intervention varied across participants, some suggesting it was less impactful for those who had pre-existing greater confidence or skills in asserting themselves:

I think it would help more people that didn't know anything about speaking up, disability, anything. I'm quite outspoken with people, but I think that other people have got a little bit more benefit than I've got.

— (GM, SA)

Whilst no sustained adverse outcomes of the intervention were identified by group members, facilitators or significant others, some group members and facilitators did report short-term negative emotional responses to two of the videos, which showed people with intellectual disabilities being victimised.

The importance of support from others when upset by any of the content was noted in most facilitator and three group member interviews. Four facilitators spoke about the value of the balance of positive and negative material, which was purposefully built into the intervention, such that each session ends on a positive message or topic.

Finally, although not directly asked about the impact on themselves, three parents highlighted the benefits of issues of disability stigma being addressed outside of the family:

It's something he needs to talk about in a group because he won't necessarily want to talk to me about it. It's always nice if somebody comes in and talks to them and makes them understand, it's nice really. I know we do it but it's hard work for us, but if it comes from somebody else I think it makes it a lot easier.

— (SO, SA)

4 | DISCUSSION

The current study suggests that it is feasible to recruit and retain established groups of people with intellectual disabilities to the STORM intervention. With limited resource, 10 groups with a total of 68 participants were recruited over a 4-month period, and a further 15 groups expressed interest in taking part, which indicates interest and a perceived need to enhance stigma resistance in people with intellectual disabilities.

Qualitative assessment indicated that the intervention was generally well received by the sub-sample interviewed and facilitators. Of note, this article presents an early-stage study and much more work is

needed to assess the intervention's impact and process issues. Some participants felt upset by seeing individuals victimised in some of the video material; while they felt well supported in the session and no adverse outcomes were reported, the respective materials require review.

Although a model of stigma resistance specific to intellectual disability has not yet been developed, it is possible to tentatively map the current qualitative results on to Firmin et al.'s (2017) framework of stigma resistance as a multifaceted and ongoing process. The model distinguishes stigma resistance at the personal, peer and public levels. At the personal level, participants in the current study vocalised beliefs in line with stigma resistance, such as having equal rights and rejecting negative judgements by others. At the peer level, participants spoke about the importance of hearing the experiences of other people with intellectual disabilities and standing up not only for themselves but also peers. Finally, at the public level, participants fed back their plans to educate others and to speak out against discrimination. Some participants decided post-STORM to become actively involved in self-advocacy.

The study took a public health approach in viewing stigma as an issue that all individuals with intellectual disabilities potentially have to face at different points in their lives. The theoretically driven and strategic decision to deliver the intervention to pre-existing groups of people with intellectual disabilities inevitably means that participants will be affected by stigma to different extents, and their ability to manage and resist stigma will vary. It could be argued that the intervention should be targeted at individuals showing negative responses to their stigmatised status, such as lower self-esteem and/or psychological distress. However, in a group intervention, the contributions of individuals who may be more able to resist stigma, for example, through modelling or self-affirmative responses, and opportunities for peer support merit further evaluation of STORM as a public health intervention for any individuals and groups who wish to take part. In addition, while some groups felt their members were already better equipped to resist stigma through previous self-advocacy work, they felt the intervention was still useful. Future research may consider how those better equipped to resist stigma could lead the delivery of the intervention and explore the benefits this may offer in relation to peer-support and modelling.

It has been proposed that the positive outcomes associated with increased stigma resistance are due to the empowering, positive effects of members of marginalised groups asserting their rights and needs against those who stigmatise them (Nabors et al., 2014). Whether interventions such as STORM have beneficial effects that equal, exceed or complement those of self-advocacy groups, which generally aim to empower and support their members in asserting their rights, is a question for further research.

4.1 | Limitations of the current study

Information about the characteristics of the sub-sample of group members interviewed was only collected with regards to gender, preventing us from examining to what extent they were representative of the full pilot

sample. Not only may they have been unrepresentative but it is also possible that this sub-sample and the significant others who agreed to be interviewed held more positive views of the STORM intervention, or generally of people with intellectual disabilities asserting their equal status and rights than those who did not respond to requests for an interview. In the qualitative interviews, despite attempts to elicit both positive and negative feedback, participants may have been more forthcoming with positive than with negative feedback.

In line with the Medical Research Council's guidance (Craig et al., 2008; Skivington et al., 2021), the results of this initial pilot help to inform future development and evaluation of the STORM intervention. The results tentatively suggest positive effects of the intervention for at least some participants, and the successful recruitment and retention of participants in the intervention suggest an appetite for the intervention amongst target groups. Going forward, key issues not examined in the present early-stage study due to resource constraints should be examined using a controlled design, including the hypothesised health and social outcomes and the impact of participant and group characteristics, as well as process issues, for example, intervention fidelity. If further evaluation were to point to the efficacy of the intervention, then the STORM manual and materials could be made freely available as a public health intervention to enhance stigma resistance in people with intellectual disabilities but, as noted, this is some way off and subject to further careful evaluation.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England. *Journal of Affective Disorders*, 187, 224–231.
- Ali, A., Strydom, A., Hassiotis, A., Williams, R., & King, M. (2008). A measure of the perceived stigma of intellectual disability. *British Journal of Psychiatry*, 193, 410–415.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18, 47–56.
- Beck, A. T. (Ed.). (1978). *Cognitive therapy of depression*. Guilford Press.

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: The new Medical Research Council guidance. *British Medical Journal*, 337, a1655.
- Emerson, E., Madden, R., Graham, H., Llewellyn, G., Hatton, C., & Robertson, J. (2011). The health of disabled people and the social determinants of health. *Public Health*, 125(3), 145–147.
- Firmin, R. L., Luther, L., Lysaker, P. H., Minor, K. S., McGrew, J. H., Cornwell, M. N., & Salyers, M. P. (2017). Stigma resistance at the personal, peer, and public levels: A new conceptual model. *Stigma and Health*, 2(3), 182–194.
- Fung, K. M., Tsang, H. W., & Cheung, W. (2011). Randomized controlled trial of the self-stigma reduction program among individuals with schizophrenia. *Psychiatry Research*, 189, 208–214.
- Gilmore, L., Campbell, J., & Cuskelly, M. (2003). Developmental expectations, personality stereotypes, and attitudes towards inclusive education: Community and teacher views of Down syndrome. *Int. Journal of Disability, Development & Education*, 50, 65–76.
- Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, 66, 521–534.
- Link, B. G., & Phelan, J. C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 363–385.
- Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 533–542.
- Luckstead, A., Drapalski, A., Calmes, C., Forbes, C., DeForge, B., & Boyd, J. (2011). Ending self-stigma: Pilot evaluation of a new intervention to reduce internalized stigma among people with mental illnesses. *Psychiatric Rehabilitation Journal*, 35(1), 51–54.
- Luoma, J. B., Kohlenberg, B. S., Hayes, S. C., Bunting, K., & Rye, A. K. (2008). Reducing self-stigma in substance abuse through acceptance and commitment therapy: Model, manual development, and pilot outcomes. *Journal of Addiction Research and Theory*, 16, 149–165.
- Martín-Baró, I. (1994). *Writings for a liberation psychology*. Harvard University Press.
- McCaughey, T. J., & Strohmer, D. C. (2005). Prototypes as an indirect measure of attitudes toward disability groups. *Rehabilitation Counseling Bulletin*, 48, 89–99.
- Nabors, L. M., Yanos, P. T., Roe, D., et al. (2014). Stereotype endorsement, metacognitive capacity, and self-esteem as predictors of stigma resistance in persons with schizophrenia. *Comprehensive Psychiatry*, 55, 792–798.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25, 166–176.
- Pescosolido, B. A., & Martin, J. K. (2015). The stigma complex. *Annual Review of Sociology*, 41, 87–116.
- Pistrang, N., Barker, C., & Humphreys, K. (2008). Mutual help groups for mental health problems: A review of effectiveness studies. *American Journal of Community Psychology*, 42(1–2), 110–121.
- Puschner, B. (2018). Peer support and global mental health. *Epidemiology and Psychiatric Sciences*, 27, 413–414.
- Richardson, L., Beadle-Brown, J., Bradshaw, J., Guest, C., Malovic, A., & Himmerich, J. (2016). “I felt that I deserved it”—experiences and implications of disability hate crime. *Tizard Learning Disability Review*, 21(2), 80–88.
- Skivington, K., Matthews, L., Simpson, S., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *British Medical Journal*, 374, n2061.
- Werner, S., & Scior, K. (2016). Interventions aimed at tackling intellectual disability stigma: What works and what still needs to be done. In K. Scior & S. Werner (Eds.), *Stigma and intellectual disability: Stepping out from the margins*. Palgrave Macmillan.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. W. W. Norton.
- Wight, D., Wimbush, E., Jepson, R., & Doi, L. (2015). Six steps in quality intervention development (6SQuID). *Journal of Epidemiology and Community Health*, 70, 520–525.

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