

**A feasibility study of a psychosocial intervention to increase
the capacity of people with intellectual disabilities to manage
and resist stigma**

Kristina Fenn

D.Clin.Psy Thesis (Volume 1), 2018

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Kristina Fenn

Date: 22nd June 2018

Overview

This study sought to further understanding within the research field of stigma resistance in people with intellectual disabilities (ID).

Part 1 comprises a systematic literature review of the psychological and social impact of self-advocacy group membership on people with ID. Twelve studies were identified and evaluated. Several outcomes were reported, including empowerment, a sense of belonging and changes to self-identity. Implications of the findings of the review include a need for quantitative studies and co-construction of research agendas with self-advocates.

Part 2 comprises a mixed methods uncontrolled feasibility study of a psychosocial intervention to increase the capacity of people with ID to manage and resist stigma. Sixty-eight participants from ten pre-existing groups of people with ID were recruited, along with their pre-existing facilitators. Findings indicated that all ten groups completed the intervention, with improvements in self-esteem and psychological distress. Qualitative feedback indicated factors affecting feasibility and suggested adaptations to inform the development of the intervention. Participants perceived improvements in stigma resistance and other areas. The recruitment rates and positive effects suggest it is worthwhile to proceed to a controlled trial of the intervention. This was a joint project together with another D.Clin.Psy trainee (Colman, 2018).

Part 3 comprises a critical and reflective appraisal of the process of conducting the study outlined in Part 2. Issues considered include the author's professional values and theoretical influences, along with a consideration of the levels of context that influenced the qualitative data collection.

Impact Statement

The current thesis informs research and clinical practice in relation to self-advocacy and stigma resistance among people with intellectual disabilities (ID). It firstly contains a literature review of studies assessing the psychological and social impact of self-advocacy group membership on people with ID. The results of this review help inform future research into self-advocacy among people with ID, namely, a need for more research using quantitative methodologies to aid the reliable assessment of outcomes and more detailed descriptions of qualitative methodologies to help readers understand how conclusions were drawn. Furthermore, the review argues for more co-construction of research agendas together with self-advocates in order to increase the role of people with ID in the process of conducting research that is about them. Notwithstanding these limitations of the current evidence base, the findings of the review illuminate the range of positive effects of self-advocacy group membership, including empowerment and a sense of belonging.

The second part of the thesis constitutes a feasibility study of a psychosocial intervention to increase the capacity of people with ID to manage and resist stigma. The initial quantitative results suggest that it is feasible to recruit to the intervention and that it led to an increase in self-esteem and reduction in psychological distress among participants. Qualitative feedback obtained from participants suggests achievable adaptations to the intervention, such as specific changes to the intervention manual, prior to future delivery and evaluation. The qualitative results also indicate participants' perceptions of the impact of the intervention, including enhanced stigma resistance, increased confidence and improved relationships. The above results inform future development and evaluation of this public health intervention, and suggest that it is worthwhile to proceed to a controlled trial.

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Acknowledgements

Thank you to Bailey Thomas Charitable Fund for their support of this project. A huge thank you to my wonderful supervisor, Katrina Scior, who provided endless guidance, support and inspiration. I also am very thankful for the brilliant research team at UCL whose ideas and tireless effort made the 'Standing Up For Myself' (STORM) study a reality: Lisa Richardson, Laurie Poole, Sophini Logeswaran, Sophie Colman and Becky Cooper. Thank you also to the external project advisors and steering group who continue to offer their time, experience and dedication to the development of STORM: Celia Brown, Paul Davies, Adelle Havard, Laura Kerr, Richard Maxfield, Harry Roche, Afia Ali, Andrew Jahoda, Richard Hastings, Jason Crabtree, Sandra Baum and Sophie Doswell. Thank you to all of the group members and facilitators in the current study who were incredibly welcoming and showed such warmth, thoughtfulness and enthusiasm when trialling the STORM programme. Thank you to Stephen Williams, and John and Anna Fenn, for their constant encouragement, patience and love.

Part 1: Literature Review

The psychological and social impact of self-advocacy group membership on people
with intellectual disabilities: A literature review

Abstract

Background: Self-advocacy aims to redress social inequalities via people speaking up for themselves, standing up for their rights, and making their own choices (People First, 1996). The self-advocacy movement by people with intellectual disabilities (ID) includes groups which bring people together in these endeavours.

Method: A review of studies examining the psychological and social impact of self-advocacy group membership on people with ID was carried out. Systematic searches of electronic databases (PsycINFO, Scopus, Web of Science, Prospero, and ProQuest's Sociology Database), together with manual searches of the reference lists and citations of articles that met the review's inclusion criteria, identified 12 studies all of which used qualitative methodology.

Results: The quality of the studies was critically appraised along with a narrative synthesis of the findings. The most frequently reported outcome was 'empowerment', and the associated outcome of 'increased confidence' was also reported in several studies. 'Belonging' and increased opportunities for social connections and relationships were also key themes in the literature. A final key outcome was changed self-identity, which appeared to be associated with changes to activities and occupations of group members.

Conclusions: Limitations of the review included difficulty categorising outcomes and the majority of the review was conducted by one reviewer. Limitations of the evidence base were a need for more detailed reporting of qualitative methodology and a lack of quantitative studies which made it difficult to assess outcomes. Implications of the review included a suggestion that the role of self-advocates in the research could be extended to co-construction of research agendas. Further involvement in research was considered particularly pertinent given the key finding of 'empowerment' resulting from self-advocacy.

1. Introduction

It is estimated that around 1.2 million people in England have an intellectual disability (ID), comprising 2% of the general population (British Institute of Learning Disabilities, 2011). Internationally, three criteria are required to be met in order for an ID diagnosis to be given: intellectual impairment, social or adaptive dysfunction combined with IQ, and early onset (British Institute of Learning Disabilities, 2011). Despite increased physical integration and improvements in service provision and societal views, people with an ID often continue to feel socially excluded and are exposed to negative perceptions and treatment by others. Aspects of this discrimination can include lower levels of power and control over their own lives, fewer contexts for exercising basic rights such as self-expression, and fewer opportunities to influence societal structures (Scior & Werner, 2015).

Self-advocacy by people with ID has been described as a social movement (Beart, Hardy & Buchan, 2004), powered by people with ID themselves, with the aim of redressing societal inequalities and injustices. Indeed, self-advocacy groups are created by members to be key self-authored spaces, the dominant narrative of which has been about speaking out, having a say, and developing skills in empowerment (Anderson & Bigby, 2017). People First, a self-advocacy organisation run by people with ID, defines self-advocacy as speaking and standing up for oneself, standing up for one's rights, making choices, being independent, and taking responsibility for oneself (Dybwad & Bersani, 1996).

Self-advocacy within the ID field seems to have first been recorded in the late twentieth century (Barnes & Walmsley, 2006), unlike self-advocacy by people with physical disabilities, which can be traced back to the nineteenth century (Campbell & Oliver, 1996). UK based self-advocacy is said to have started in 1984 when 'People First London Boroughs' was founded (Barnes & Walmsley, 2006). In the mid-1980s in the UK, self-advocacy groups grew mainly within clinical service settings, and then around the late 1980s self-advocacy attracted research and

publications focused on people's life-stories and experiences (Barnes & Walmsley, 2006).

Crawley (1990) later developed a typology of self-advocacy groups, focusing on the constitutional and structural facets. Firstly, some self-advocacy groups are politically, financially and organisationally 'autonomous', e.g. the People First movement. Secondly, some groups developed out of existing, professionally-led organisations (e.g. Mencap). Thirdly, some groups follow a 'coalition model' which is affiliation with wider disability civil rights organisations (e.g. citizen advocacy). Finally, some groups continue to be 'service-based' (e.g. within day centres or clinical services).

To appreciate the current impact and positioning of self-advocacy groups, Goodley (1997) argued that they must be considered in the context of wider societal and theoretical discourses about disability. In particular, the individual model of disability (which locates disability *within* the individual), gives rise to discourses of impairment and dependency which are in contradiction with the values of self-advocacy (e.g. self-determination and capacity). It has been argued that self-advocacy is best understood and practised when it is grounded in a social model of disability (Oliver & Barnes, 1998), which attends to the ways society disables people with disabilities (e.g. through exclusion, discrimination and stigmatisation). The social model of disability focuses on the need for societal change and encourages contexts for the basic rights of self-expression and growth (Oliver & Barnes, 1998). Within this model, people given a disability label are seen as the most able people to explain the effects of a disabling society and self-advocacy is seen as a continually progressive and emancipatory activity (Goodley, 1997).

Existing studies have considered the effects of self-advocacy by people with ID at the individual, collective and public level. At the individual level, studies have looked at the impact of membership of self-advocacy groups on self-advocates themselves. For example, Anderson and Bigby (2017) found that engagement with

self-advocacy groups provided members with access to collegiality, respectful relationships, interesting activities, a sense of ownership, and control. Some researchers (e.g. Goodley, 1997) have described a tension between self-advocacy as a means for *individuals* to 'speak up' and affirm their preferred identities, and self-advocacy as a *collective* movement representing the interests of a particular group. Others have focused on the importance of action and change resulting from self-advocacy, including a shift of power, with self-advocates influencing services and structures (Aspis, 2002). Additionally, self-advocates can challenge stereotypes through these shifts in power and by having more control about the narratives that are told about people ascribed the label of ID. In this way, it is hoped that there are 'spillover' effects of self-advocacy groups in breaking down negativity and stigma surrounding ID (Anderson & Bigby, 2017).

The impact of self-advocacy at the political level, and indeed the impact of policy and legislation on self-advocacy groups, has also been considered. The *Valuing People* White Paper (Department of Health, 2001) emphasised 'user empowerment' and proposed that people with ID should have a 'voice'. Some researchers have written about the challenges of government support which necessitates, to some degree, partnership between government and self-advocacy organisations aiming to speak out against existing societal views and structures (Barnes & Warmley, 2006). On the one hand, there is a responsibility on central government to foster inclusive values and create the conditions within which self-advocacy can develop. On the other hand, self-advocacy groups can become subject to the same conditions as other services: contracts, targets and imposed deadlines (Barnes & Warmley, 2006). Furthermore, the challenges of remaining financially afloat have become a dominant theme for self-advocacy groups in recent years. Limited and diminishing government funding and lack of recent explicit policy support threatens their sustainability (Anderson & Bigby, 2017).

The current review aims to draw together the existing literature on the impact of self-advocacy group membership. The scope of the review is limited to psychological and social effects on self-advocates themselves. The review seeks to draw together the evidence on the range of effects of self-advocacy group membership and to consider the strength of the evidence base. This is important to enhance our understanding of self-advocacy groups and for informing future decision-making. Firstly, elucidation of what the positive effects of self-advocacy are may help evidence the need for continued funding. Secondly, highlighting the nature of these effects may help consideration of whether and how existing policy supports the conditions for these effects to occur. Moreover, it may inform changes to policy on how best to create the contexts for self-advocacy. Finally, it is hoped that the review will highlight any areas that have so far been neglected in research and therefore inform future research objectives.

1.1. Review questions

This review set out to address two questions:

1. What is the psychological and social impact of self-advocacy group membership on group members with ID?
2. What are future research directions that would advance the literature base?

2. Method

2.1. Search strategy

Figure 1 illustrates the search strategy and study selection process. The review is based on a search of articles published prior to August 2017. The electronic databases searched were PsycINFO, Scopus, Web of Science, Prospero and ProQuest's Sociology Database. Search terms were used to identify articles pertaining to: (i) intellectual disability, (ii) self-advocacy, and (iii) psychological or social impact (on identity, sense of belonging, empowerment, self-esteem, confidence, mental health, wellbeing, engagement in community, and activism).

From the search of electronic databases, 350 articles exported to EndNote and 40 duplicates were removed, leaving 310 articles. After the reviewer screened the titles for eligibility, 277 were removed, leaving 33 articles. After this stage, twenty additional studies were identified by searching for the term “self-advocacy” on ID journal websites (British Journal of Learning Disabilities; Disability and Society; and Journal of Applied Research in Intellectual Disabilities) and within the publications of a key researcher in the field, Christine Bigby.

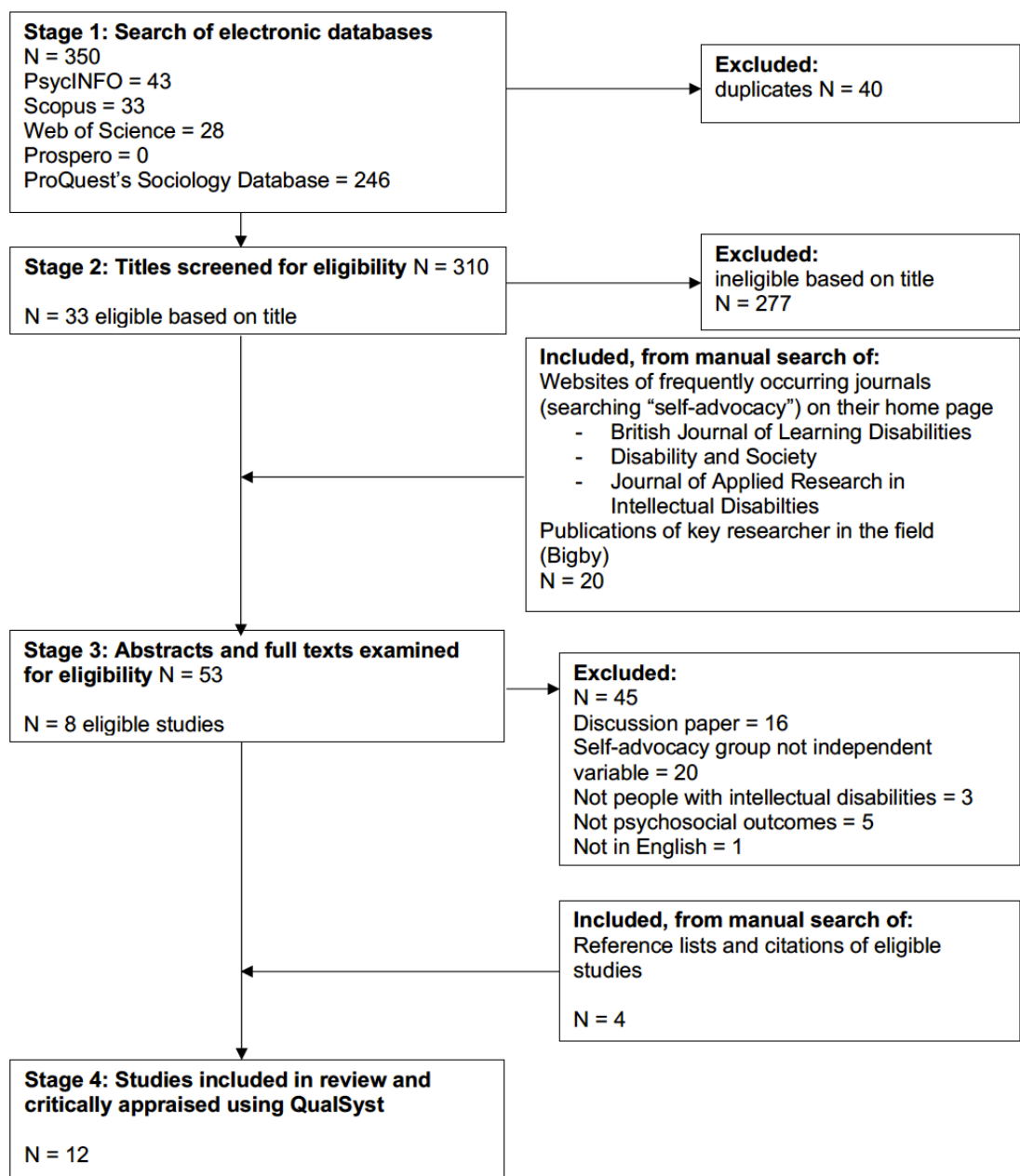


Figure 1. Search strategy and study selection process

2.2. Study selection

The above search and selection process yielded 53 articles in total. The abstracts and full texts of these articles were read, with consideration to the parameters of the current review, and therefore the inclusion and exclusion criteria listed in sections 2.2.1. and 2.2.2. below. After reading the abstracts and full texts of the 53 studies, 45 were excluded: 16 of the articles were excluded because they were discussion papers; twenty articles were excluded because they did not describe the impact of self-advocacy group membership (as the independent variable); three articles were excluded because the participants did not have intellectual disabilities; five articles were excluded because they did not report psychosocial outcomes; and one study was excluded because it was not published in English. Finally, four further studies were identified from a manual search of the reference lists and citations of the eight eligible studies. This process resulted in 12 studies being retained which assessed the impact of self-advocacy group membership on people with ID.

2.2.1. Inclusion criteria

1. Published in English, given the first language of the reviewer.
2. Published before August 2017, the time at which the search was conducted
3. Participants were described as having 'intellectual disabilities', 'intellectual disability', 'learning disabilities' or 'learning disability'.
4. Considered self-advocacy groups to be the independent variable.
5. All designs were permitted in the current review, including experimental and retrospective designs.
6. All methods were permitted in the current review, including quantitative and/or qualitative methods.
7. Studies reported original data on any measure of impact or outcome of self-advocacy group membership.

2.2.2. Exclusion criteria

1. Participants were described as having specific learning difficulties ('dyslexia', 'dyspraxia' and 'dyscalculia'), as opposed to intellectual disabilities.
2. Studies which investigated clinical interventions, i.e. group programmes or interventions in healthcare settings
3. Discussion papers

2.3. Quality rating of the studies

The QualSyst (Kmet, Lee & Cook, 2004) tool was employed to appraise critically the quality of the articles in this review. This tool assesses the quality of research articles of various designs and describes quality criteria for quantitative (14 items) and for qualitative (10 items) research articles. For the current review, the qualitative criteria were employed, see Table 1.

Table 1. QualSyst criteria for assessing quality of qualitative studies

Item number	Criterion
1	Question/objective sufficiently described?
2	Study design evident and appropriate?
3	Context for the study clear?
4	Connection to a theoretical framework/wider body of knowledge?
5	Sampling strategy described, relevant and justified?
6	Data collection methods clearly described and systematic?
7	Data analysis clearly described and systematic
8	Use of verification procedure(s) to establish credibility?
9	Conclusions supported by the results?
10	Reflexivity of the account?

Each article was scored on the 10 criteria, with possible item scores ranging from 0 to 2 (0 = No; 1 = Partial; 2 = Yes). Items include ratings of the sampling strategy, data collection methods and reflexivity of the account (see table 1 for full list of

items). The scoring system has been shown to have good inter-rater reliability (Kmet et al., 2004). In order to increase the reliability of the ratings, a second reviewer used the QualSyst to independently rate 25% of the articles. Discrepancies between scores assigned by the primary and secondary reviewer were discussed and agreements reached before the primary reviewer scored the remaining articles. A total quality score for each article was calculated by summing individual item scores and dividing the sum by the possible total score (20). The ratings were used to provide some indication of the quality of the articles, although Kmet et al. did not provide cut-offs. Table 2 shows each article's scores and overall quality rating, the latter of which ranged from 0.4 to 0.9 (from a possible range of 0 to 1), with an average of 0.66, suggesting the quality of the articles was variable.

Considering the 12 studies altogether, the quality was highest in relation to the descriptions of the studies' questions, designs and contexts. For each of these three criteria, at least eight studies fully met the quality standard and the remaining studies partially met the standard. For each of the following criteria, approximately half of the studies fully met the quality standard: connection to a theoretical framework; description and systematic-nature of data analysis; use of verification procedures to establish credibility; and conclusions supported by the results.

Overall, the quality of the studies was weaker in relation to the descriptions and nature of the sampling strategies and data collection methods. Two studies (Caldwell, 2010; Mineur et al., 2017) fully met the quality standard for describing their sampling strategies such that they were clearly relevant and justified. Three studies (Beart et al., 2004; Caldwell, 2010; Clarke et al., 2015) fully met the quality standard for clearly describing systematic data collection methods. The quality of the studies was lowest in the area of reflexivity of the accounts. One of the articles (Caldwell, 2010) explicitly assessed the likely impact of the researcher's personal characteristics and the methods used on the data obtained. In three of the studies (Beart et al., 2004; Clifford, 2013; Gilmartin & Slevin, 2009), there was mention of

possible sources of influence on the data, but the likely impact of the influences was not discussed. The remaining eight studies showed no evidence of reflexivity in the reports.

Table 2. Quality ratings using the QualSyst criteria for qualitative studies

Study	QualSyst criteria item scores										Quality score (0-1)
	(0=no, 1=partial, 2=yes)										
	1	2	3	4	5	6	7	8	9	10	
Anderson & Bigby (2017)	2	2	2	1	1	1	2	0	2	0	0.65
Beart, Hardy & Buchan (2004)	2	1	2	2	0	2	2	2	2	1	0.8
Caldwell (2010)	2	2	2	2	2	2	1	2	1	2	0.9
Clarke, Camilleri & Goding (2015)	1	2	2	1	1	2	2	2	2	0	0.75
Clifford (2013)	1	1	1	1	0	1	1	0	1	1	0.4
Frawley & Bigby (2015)	1	2	2	2	1	1	1	2	2	0	0.7
Gilmartin & Slevin (2009)	2	1	2	1	1	1	2	2	2	1	0.75
McNally (2003)	2	2	1	1	1	1	1	0	1	0	0.5
Miller (2015)	2	1	2	2	1	1	1	0	1	0	0.55
Mineur, Tideman & Mallander (2017)	2	2	2	1	2	1	2	2	2	0	0.8
Tideman and Svensson (2015)	2	2	2	2	0	1	1	0	1	0	0.55
Zyta and Ćwirynkało (2016)	2	2	2	1	1	1	1	0	1	0	0.55

3. Results

The search identified 12 studies, all of which used qualitative methodologies. Four of the studies took place in the United Kingdom (UK), two in the United States (US), two in Sweden, one in Poland, one in Ireland, one in Australia, and one study had participants from both Australia and the UK. The earliest study took place in 2003, one in 2004, one in 2009, one in 2010, one in 2013, four in 2015, one in 2016 and two in 2017.

Three of the studies broadly focused on the lived experiences of belonging to a self-advocacy group. One stated its focus was on both the experience of belonging to a self-advocacy group and the influence on members' lives. Three of the studies considered the effects and influence of self-advocacy group membership on social identity, social participation and social inclusion. One study specifically focused on the impact of engagement in a self-advocacy group on identity and daily life. The four remaining studies each had a specific focus, respectively looking at the impact of self-advocacy group membership on: leadership development, empowerment, change in organisational culture, and within a new (Swedish) welfare context.

Two of the studies did not report their sample sizes. Among the remaining ten studies, the sample sizes ranged from six to 53 self-advocates, with an average sample size of 19. Seven of the studies did not report how long the participants had been members of a self-advocacy group. Three studies' participants had been members of self-advocacy groups for at least six months; one study's participants had been involved in self-advocacy for more than 25 years; and one study recruited participants who had been identified as leaders in the self-advocacy movement.

Six of the studies collected data solely via semi-structured interviews; two used both semi-structured interviews and group interviews; one used observations of monthly group meetings; one used repeated interviews and observations of meetings; one used observations, semi-structured interviews and focus groups; and one study collected data via a postal survey. To analyse the data, five of the studies used (constructivist) grounded theory (Anderson & Bigby, 2017, Beart, Hardy & Buchan, 2004; Caldwell, 2010; Clifford, 2013; Ćwirynkało, 2016); two used thematic analysis (Clarke, Camilleri & Goding, 2015; Frawley & Bigby 2015); one used cooperative inquiry (Tideman and Svensson, 2015); one used a phenomenological methodology (Gilmartin & Slevin, 2009); one used an interpretative abductive approach (Mineur, Tideman & Mallander, 2017); the survey study used narrative

description of responses (McNally, 2003); and one study did not report how the data were analysed (Miller, 2015). See table 3 for an overview of the studies.

Table 3. Samples, data collection and analysis methods of the studies

Authors (year)	Study focus	Location and Sample	Data collection methods	Data analysis
Anderson & Bigby (2017)	Effects of self-advocacy group membership on social identity	Australia and UK; 25 members from 6 self-advocacy groups	Semi-structured interviews	Constructivist grounded theory
Beart, Hardy & Buchan (2004)	Experience and individual impact of self-advocacy group membership	UK; 8 members involved in self-advocacy for at least 6 months	Semi-structured interviews	Grounded theory
Caldwell (2010)	Leadership in self-advocacy	US; 13 leaders in the self-advocacy movement	Semi-structured interviews	Grounded theory
Clarke, Camilleri & Goding (2015)	Experiences, benefits and difficulties, of being part of a self-advocacy group	UK; 6 members involved in self-advocacy for at least 6 months	Semi-structured individual and group interviews	Thematic analysis
Clifford (2013)	Acts of empowerment	US; A self-advocacy group observed over a two-year period	Observations of a monthly group meeting	Grounded theory
Frawley & Bigby (2015)	Reflections on being long-term members of a self-advocacy group and how membership influenced social inclusion	Australia; 12 members involved in self-advocacy for more than 25 years	Interviews	Thematic analysis
Gilmartin & Slevin (2009)	Lived experiences of belonging to a self-advocacy group	Ireland; 13 members from 3 self-advocacy groups based in day centres,	Semi-structured interviews	Phenomenological methodology

		involved in self-advocacy group for at least 6 months		
McNally (2003)	Experience of self-advocacy and its influence on self-advocates' lives	England; 53 self-advocates	Survey	Narrative description of responses
Miller (2015)	Impact of a self-advocacy group introduced to change organisational culture (openness and transparency)	UK; A monthly self-advocacy group in an inpatient, low-secure service for men with ID and mental health needs. Participants were group members, facilitators and staff.	Observations, semi-structured interviews and focus groups.	Not stated
Mineur, Tideman & Mallander (2017)	Impact of engagement in a self-advocacy group on daily life and identity	Sweden; 26 members from 6 self-advocacy groups	Semi-structured interviews	Interpretative abductive approach
Tideman and Svensson (2015)	The significance of self-advocacy in a new (Swedish) welfare context	Sweden; 12 members of two self-advocacy groups	Repeated interviews and observations of meetings	Cooperative inquiry
Zyta and Ćwirynkało (2016)	Social participation and social identities	Poland; 18 members of self-advocacy groups	Semi-structured focus group interviews	Constructivist grounded theory

3.1. Overview of the studies' findings

A summary of the findings of the studies on psychological and social outcomes of self-advocacy group membership for people with ID is provided in table 4, along with details of which studies reported each outcome. Across the twelve studies, five psychosocial outcomes of self-advocacy group membership were reported. The most commonly occurring were 'empowerment and speaking up' (reported in eight studies) and 'belonging and mutual support' (in five studies). Changes to self- and social identity were reported in four and two studies, respectively. One study reported the outcome as increase in leadership. The only psychological outcome found was increases in confidence, which was reported in four studies. The social outcomes of 'social connections and relationships' and 'meaningful occupation/activities' were reported in five and three studies, respectively.

Table 4. Summary of reported outcomes of self-advocacy group membership

Authors (year); quality rating	Psychosocial				Psychological		Social	
	Empowerment	Belonging	Self-identity	Social identity	Leadership	Confidence	Social connections and relationships	Meaningful occupation/activities
Anderson & Bigby (2017); 0.65	Y	Y	Y	Y	-	Y	Y	Y
Beart, Hardy & Buchan (2004); 0.8	-	-	Y	-	-	-	-	-
Caldwell (2010); 0.9	-	-	-	-	Y	-	-	-
Clarke, Camilleri & Goding (2015); 0.75	Y	Y	-	-	-	Y	-	-
Clifford (2013); 0.4	Y	-	-	-	-	-	-	-
Frawley & Bigby (2015); 0.7	-	Y	-	-	-	-	Y	Y
Gilmartin & Slevin (2009); 0.75	Y	Y	Y	-	-	-	Y	-
McNally (2003); 0.5	Y	Y	-	-	-	-	Y	-
Miller (2015); 0.55	Y	-	-	-	-	Y	-	-
Mineur, Tideman & Mallander (2017); 0.8	-	-	Y	-	-	-	-	-
Tideman and Svensson (2015); 0.55	Y	-	-	Y	-	-	-	-
Zyta and Ćwirynkała (2016); 0.55	Y	-	-	-	-	Y	Y	Y

Each of these outcomes will be considered in further detail below, including consideration of the meaning of concepts (e.g. empowerment), the ways in which the studies sought to assess the impact of self-advocacy, the quality of the studies and therefore weight of the findings.

3.2. Psychosocial Outcomes

3.2.1. Empowerment

Empowerment was described by social scientist, Julian Rappaport (1987), as a “concept (that) suggests both individual determination over one’s life and democratic participation in the life of one’s community...both a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights” (Rappaport, 1987, p1). Furthermore, he suggested that, “empowerment is a process, a mechanism by which people, organizations, and communities gain mastery over their affairs. Consequently, empowerment will look different in its manifest content for different people, organizations, and settings” (Rappoport, 1987, p2).

Empowerment was the most frequently reported outcome in the studies reviewed, emerging as a theme in eight studies examining the impact of self-advocacy group membership for people with ID. As indicated in the definition provided above, ‘empowerment’ covers a broad range of phenomena and can be operationalised in different ways. The studies used observations, individual and group interviews to collect data, and a variety of qualitative methods to analyse the data, including grounded theory, thematic analysis and cooperative inquiry. One study used a survey with free-text spaces for responses.

Empowerment was reported at an individual and group basis. For example, participants in Tideman and Svensson’s (2015) study reported increased power over personal economic resources; and self-advocates in Gilmartin and Slevin’s (2009) study shared experiences of learning about their rights and together affecting change (e.g. by writing a letter to the local authority. Miller (2015) assessed the

impact of a self-advocacy group in an inpatient, low-secure service for men with ID and mental health needs. It was reported that self-advocacy group membership helped the group members influence service provision (e.g. leading to the refurbishment of an outside area) and increased use of the complaints process. The quality rating of these studies ranged from 0.4 to 0.75, with an average of 0.59, indicating mostly low to medium quality. Appearing in eight out of the twelve studies, the broad outcome of empowerment (in different forms) appears to be a robust finding, though mostly based on less than strong research methods.

3.2.2. Belonging

This has been defined as, “a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together” (McMillan & Chavis, 1986, p9). Belonging emerged as an outcome of group membership in five studies, conducted in the UK and Australia. Four of these used individual interviews to access the views of self-advocates (two analysed the data thematically; one using phenomenological methodology, one grounded theory) and one was based on survey responses. For example, in Frawley and Bigby’s (2015) interviews with long-term self-advocates who had each been involved with a group for more than 25 years, they found that participants had gained a sense of belonging through their involvement in self-advocacy. In McNally’s (2003) survey of self-advocates in England, mutual support gained through self-advocacy group membership was reported to be an important issue for respondents. The quality rating of the studies ranged from 0.5 to 0.75, with an average of 0.67). Reported in five of the twelve studies, a sense of belonging appears to be an outcome that some self-advocates report benefitting from, but one that is not always spoken of as part of the experience of self-advocacy.

3.2.3. Changes to self-identity

Also termed ‘self-concept’, this refers to a collection of beliefs about oneself (Leflot et al., 2010). Four studies reported changes to self-identity as an outcome of

self-advocacy group membership. These studies took place in Australia, the UK and Sweden. The data in all of these studies were from interviews with self-advocates. The data analysis methods included grounded theory, a phenomenological approach and an interpretative abductive approach.

Anderson and Bigby (2017) found that self-advocacy group membership opened up possibilities for multiple positive self-identities for the self-advocates, including being an independent person. Beart et al. (2004) found that the core theme to emerge from all (eight) of their interviews with self-advocates was that of 'changing selves', which they concluded to be a process of change in individual self-concept. They found that participants described themselves in new ways in comparison to their past selves, for example as being respected and having status. In the study by Mineur et al. (2017), the authors reported changed self-perceptions, with participants seeing themselves as more skilled, social and confident.

The quality ratings of these four studies ranged from 0.65 to 0.8, with an average of 0.75, which is higher than the ratings for some other findings in the current review. Lending particular weight to this outcome, the study by Beart et al. (2004) had a quality rating of 0.8 and reported changes to self-concept to be a main finding.

3.2.4. Changes to social identity

Tajfel and Turner (1979) described social identity as a person's sense of who they are based on their group membership(s). Although group membership could be seen as central to self-advocacy groups, interestingly changes to social identity were reported in only two studies, giving this outcome perhaps less weight. Anderson and Bigby's (2017) study which had a quality rating of 0.65, found that self-advocacy group membership and associated participation, e.g. in community education programmes, afforded members the opportunity to assume the social identity of 'expert', and the organisation of the meetings provided the opportunity for members to take up the social identity of 'a business-like person'. Tideman and

Svensson's (2015) study which had a quality rating of 0.55, found that group members reported self-advocacy membership helped participants criticise and oppose the social identity they felt they had been assigned by society - that of an intellectually disabled person, with associated characteristics such as vulnerability – and to express a desire and endeavor to be seen as a person with many different roles and a unique multiple identity.

3.2.5. Leadership

This was specifically focused on in Caldwell's (2010) study. Four major themes were identified: disability oppression and resistance through self-advocacy; environmental support for leadership development and relationships afforded to members through the groups; leadership skill development (e.g. comfort in public speaking) and the need for advanced leadership opportunities (outside of the self-advocacy movement). This study had the highest quality rating (0.9) of the twelve studies. However, impact on leadership skills and opportunities was not reported as an outcome of self-advocacy group membership in the other studies reviewed.

3.3. Psychological Outcomes

3.3.1. Confidence

Four studies reported increased confidence as an outcome of self-advocacy group membership. The quality ratings of these studies ranged from 0.55 to 0.75 (average 0.63). From their interviews with self-advocates, Clarke et al. (2015) found that increased confidence, for example in speaking to other people, was reported by several participants. Participants in Miller's (2015) study reported increased confidence in self-advocacy group members to share their perspectives inside and outside of the group. Zyta and Ówirynkało (2016) found that self-advocates in their study spoke of gaining confidence and courage to cope with difficult situations, including speaking publicly. It is interesting that in these three studies, increased confidence was in particular related to speaking to others, sharing perspectives and coping with difficult situations, including speaking publicly. These increases in

confidence appear to overlap with aspects of what could be considered to be empowerment.

3.4. Social Outcomes

3.4.1. Social connections and relationships

Increases in social connections and relationships were found to be outcomes of self-advocacy group membership in five of the studies. The quality of the studies ranged from 0.5 to 0.75 (average 0.63). Participants in Zyta and Ćwirynkało's (2016) study reported that the groups provided new opportunities to develop relationships. Similarly, the self-advocates interviewed by Frawley and Bigby (2015) conveyed that they had gained new social connections through their involvement in self-advocacy. Expanded social networks emerged as a theme in all of the interviews conducted by Gilmartin and Slevin (2009), including subsequent socialising with other self-advocates outside of meetings. Increased social connections and relationships, specifically with other self-advocates, appears to be a robust finding.

3.4.2. Meaningful occupation and activities

Three studies found self-advocacy group membership resulted in increased opportunities for occupation and activities. The quality ratings of these studies ranged from 0.55 to 0.7 (average 0.63). Frawley and Bigby (2015) found that their participants spoke about gaining purposeful occupation through their involvement in self-advocacy, including paid project work, lobbying and management. The self-advocates in Zyta and Ćwirynkało's (2016) study reported that the groups provided new opportunities to participate in different activities, helping them to have interesting leisure time and contributing to the sense of being a useful person. Similarly, in Anderson and Bigby's (2017) study, increased occupation and activity related to self-advocacy involvement contributed to members viewing themselves as 'a person who is engaged in life'. Increased occupation and activity was reported by only three studies. However, it is interesting to note the relationship between

increased occupation and how group members view themselves (i.e. their self-concept, changes to which were reported in four studies, as already discussed).

4. Discussion

4.1. Key findings

The twelve studies reviewed reported a range of psychological and social outcomes of self-advocacy by persons with ID. The consistency of findings and quality of the studies can help guide which findings to attach more weight to. The most frequently reported finding (found in eight studies) was the psychosocial outcome of empowerment. Additionally, increases in confidence were particularly in relation to aspects of empowerment such as sharing perspectives and speaking to others. Increases in empowerment and confidence in speaking up are perhaps not surprising outcomes as they are very much in line with the aims of the self-advocacy movement which include speaking and standing up for oneself, standing up for one's rights and making choices (Dybwad & Bersani, 1996).

A second key finding was the positive effect of self-advocacy on the psychosocial outcome of a sense of 'belonging' (to the self-advocacy group), reported in five of the studies, and the closely linked social outcome of increased social connections and relationships (reported in four of the same studies as 'belonging' and one other study). Increased opportunities for social connections and relationships, and a related sense of belonging, therefore appear to be key themes of self-advocacy group membership.

A final key benefit of self-advocacy reported by the reviewed studies concerns changes to self-identity, which appear to be brought about by changes to activities and occupations with which members were engaged. Changes to self-identity were reported in four studies with relatively high-quality ratings (average of 0.75, compared to the average of all twelve studies which was 0.66). Changes to self-identity included seeing oneself as more skilled, respected and having status. Changes to activities and occupations as a result of self-advocacy group

membership (reported in three studies) appear to be one mechanism through which group members experienced changes to self-identity.

Interestingly, changes to social identity were reported in only two of the studies which included changes such as seeing oneself as 'business-like person' and an 'expert'. Given the group nature of self-advocacy, it is perhaps surprising that changes to social identity were not reported in more of the studies. However, it may be that changes to social identity were captured under other themes such as 'belonging' and changes to self-identity. For example, seeing oneself as 'respected' and 'having status' is clearly grounded in social appraisals and therefore could be considered to relate to social as well as self-identity.

4.2. Limitations of the current review

A difficulty encountered in conducting the current review related to these issues of interpretation; when reviewing the studies, it was difficult to decide how to group the outcomes. For example, one study reported "changes in self-perception", with participants seeing themselves as more confident (a psychosocial outcome), whereas another study reported "an increase in confidence" (a psychological outcome). When these differences in categorisation arose, the outcomes were categorised in line with the authors' interpretations. It may have been beneficial for thematic analysis to have been used to review the findings and group together themes emerging across the twelve studies. However, it could also be argued that doing so would have added in another researcher's particular interpretations of self-advocates' experiences.

Two reviewers conducted the quality rating for 25% of the studies. The current review was otherwise conducted by one reviewer, increasing the chance of individual bias and the possible occurrence of human error. Furthermore, only studies published in English were included which may have limited the comprehensiveness of this review.

4.3. Limitations of the evidence

Given the important place self-advocacy has assumed within the ID field, the fact that only 12 studies were identified that assess the outcomes of self-advocacy for group members indicates that the evidence for self-advocacy in this field is thin. In addition, few of the reviewed studies were rated as of high quality and none used a quantitative methodology or the gold standard for evaluating the outcome of any intervention, randomised controlled designs (RCTs). These factors make it difficult to draw firm conclusions about the outcomes of self-advocacy for group members with ID. In studies addressing this question, there is an overall need for more detailed descriptions and justifications of data collection methods and analysis, with clear links to how conclusions were drawn. Such descriptions may be aided by the inclusion of researcher reflexivity in the accounts to help the reader understand why the researcher chose a particular sample, line of enquiry and interpretive framework, and the implications of these decisions on their findings. Even with these improvements in the reporting of qualitative studies, the lack of quantitative studies and particularly RCTs makes it very difficult to reliably assess outcomes related to self-advocacy group membership.

4.4. Implications for future practice and research

The studies at the heart of the current review constitute an emerging evidence base; indeed, seven of the twelve studies were published within the preceding three years. The findings reported help to elucidate the substantial and wide-ranging positive impact that self-advocacy group membership has on the psychological and social wellbeing of people with ID. Although the limitation of only having qualitative evidence has been noted above, the use of qualitative methods does allow exploration of the lived experiences of self-advocates, in line with Goodey's (2005) assertion that the lived reality of self-advocacy needs to be foregrounded in any attempt to understand its impact.

Extending this central role of self-advocates, future research may benefit from a collaborative action-oriented reflexive approach to researching the lived experience of people with ID (Dowse, 2009). Such an approach places greater emphasis on mutuality and the co-construction of research agendas together with self-advocates, including interpretative frames and assigned meanings. Indeed, given the inclusion of “speaking for yourself” and “making choices” in People First’s (1996) definition of self-advocacy, an explicitly emancipatory approach to research may be pertinent to research in this area.

In relation to policy and the practice of self-advocacy, it is interesting to note that empowerment was indeed reported most frequently in the studies reviewed, as one might expect. Within an emancipatory and social model of disability, how other people such as healthcare professionals and policy makers position themselves in relation to self-advocates is important, as ‘empowerment’ can be seen as based on an assumption of the powerful giving power to the weak (Bhavnani, 1990). For example, others seeking to ‘empower’ people with ID can risk yet again ascribing a victim status to people with ID, yet the politics of self-advocacy clearly indicate a resilience in the face of a disabling world (Goodley, 2005). Therefore, in practice and policy as well as research, there should be efforts for others to take an ‘ally’ role with clear opportunities and support for self-advocates to drive the political agenda and direction of self-advocacy.

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Part 2: Empirical Paper

A feasibility study of a psychosocial intervention to increase the capacity of people
with intellectual disabilities to manage and resist stigma

ABSTRACT

Background: Efforts have been made to reduce stigma experienced by people with intellectual disabilities (ID), mostly targeting the interpersonal and structural levels of stigma. Intrapersonal interventions to reduce self-stigma have been developed for other populations, such as people living with serious mental health problems. There are no published evaluations of intrapersonal interventions that explicitly aim to help people with ID to manage and resist stigma.

Method: This uncontrolled feasibility study involved the development and testing of an intervention to increase the capacity of people with ID to manage and resist stigma. The intervention consists of five manualised sessions delivered by facilitators of self-advocacy, social and educational groups for people with ID. Recruitment and retention rates were collected, along with pre- to post-intervention quantitative data on self-esteem and psychological distress. Qualitative interviews were conducted and analysed using framework analysis (Ritchie & Spencer, 1994).

Results: Sixty-eight participants from ten pre-existing groups were recruited. All groups completed the intervention. Analysis of pre-post intervention cases showed a small increase in self-esteem ($d = 0.43$, $N = 44$) and a small reduction in psychological distress ($d = -0.16$, $N = 46$). Qualitative feedback identified factors affecting feasibility, favourite aspects and suggested adaptations. Perceptions of the intervention's effects included enhanced stigma resistance. Less of an impact was perceived by self-advocacy groups with prior involvement in stigma resistance.

Conclusions: The results inform future development and evaluation of the intervention. Positive effects show benefits to participants, qualitative data suggest achievable adaptations to the intervention and recruitment rates indicate it is feasible to proceed to a controlled trial. Future evaluation of the intervention should consider factors such as treatment dosage and group size. Finally, results are considered in the wider context of stigma resistance, peer support and self-advocacy.

1. Introduction

It is estimated that around 1.2 million people in England have an intellectual disability (ID), comprising 2% of the general population (British Institute of Learning Disabilities, 2011). A review of the research evidence concluded that 'intellectual disability' is a highly dominant and stigmatising label (Beart et al., 2005). Stigma can be conceptualised as a devalued social identity (Pescosolido & Martin, 2015), and self-stigma as the degree to which individuals internalise negative judgments and stereotypes about their label or group (Corrigan & Watson, 2002). Self-stigma is associated with multiple negative outcomes including increased mental health problems, and decreased hope and self-esteem (Jahoda et al., 2010; Livingston & Boyd, 2010). In turn, research has consistently shown that self-esteem plays a significant role in the development and maintenance of mental health problems, including anxiety and depression (Sowislo & Orth, 2013), and multiple health and life outcomes (Mann, Hosman, Schaalma et al, 2004; Orth, Robins & Widaman, 2012).

1.1. Interventions aimed at reducing stigma

As shown in Figure 1, efforts aimed at reducing stigma associated with ID are needed at several interacting levels; namely, the structural, interpersonal, familial and intrapersonal level. Interventions at the intrapersonal level (i.e. self-stigma) have been developed in various fields, including in relation to people with serious mental health problems (Fung et al., 2011, Luckstead et al., 2011) and substance abuse (Luoma et al., 2008).

They aim to reduce self-stigma by encouraging participants to question and distance themselves from negative stereotypes, and ultimately to bolster individuals' 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 acting against negative attitudes. Stigma resistance has been linked with improved recovery outcomes for people with serious mental problems (Firmin et al., 2017).

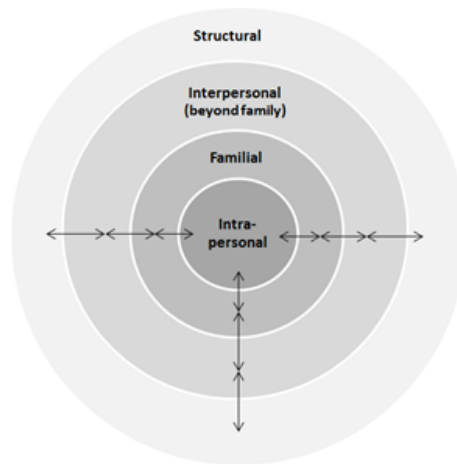


Figure 1: Multi-level model of intellectual disability stigma change interventions (Source: Scior & Werner, 2016)

Stigma resistance fits within an empowerment model of developing resilience, which views stigmatised people not only as targets who try to avoid negative outcomes, but also as people who actively try to make positive outcomes (Oyserman & Swim, 2001). Stigma resistance is described as an ongoing and active process that involves the use of experiences, knowledge, and skills at three levels: personal, peer and public (Firman, 2017). Stigma resistance can, for example, involve understanding one's own rights (personal level), sharing experiences to help others (peer level), and engagement in social activism (public level).

To date, there have been no published evaluations of intrapersonal level interventions that explicitly aim to empower people with ID to manage and resist stigma. Given the negative impact of carrying a stigmatising label, it is hoped that developing effective ways of increasing the capacity of people with ID to manage and resist stigma will decrease their self-stigmatisation and have a positive effect on associated outcomes, including self-esteem and psychological distress.

1.2 Rationale of the study

The current study aimed to evaluate the feasibility and acceptability of a newly developed psychosocial group intervention focused on stigma management and resistance, with an intended impact on the associated outcomes of self-esteem

and psychological distress in people with ID. The effectiveness of an intervention depends on its design and evaluation (Speller, Learmonth & Harrison, 1997). The Medical Research Council (2008) emphasised that feasibility studies are an essential step in the development, testing and adaptation of an intervention, prior to piloting and large-scale evaluation. As such, this small scale study is located in the early stages of the development of a new complex intervention. In line with the MRC's (2008) guidance, the study was primarily concerned with testing the feasibility of delivering the intervention and understanding participants' experiences of the intervention (in terms of its feasibility, acceptability and perceived impact). The current study aimed to inform how feasible and worthwhile a pilot and larger-scale trial of the intervention would be in the future. The research questions were formulated in line with the MRC (2008) guidance.

1.3. Research questions

Quantitative questions:

- a) What are the recruitment and retention rates of participants in the intervention?
- b) Do initial data suggest that the intervention is likely to result in improved self-esteem and reduced psychological distress, and not cause unintended harm?

Qualitative questions:

- c) For facilitators, what key factors affect the feasibility of delivering the intervention?
- d) For participants and facilitators, what key factors affect the acceptability of the intervention?
- e) What are participants' and facilitators' perceptions of the intervention's impact?

2. Methods

2.1. Participants

The study involved 68 participants (38 men, 30 women) who were members of ten pre-existing groups run for people aged 16 years and above with mild to moderate ID (six self-advocacy groups, three day service groups, and one group of students in a college), see Table 1.

When offered four options, 52 participants identified themselves as 'White British/White Other'; seven as 'Black British/African/Caribbean/Black Other'; four as 'Asian British/Asian Other'; and one as 'Other' (four missing). Sixteen participants were aged between 16 – 24 years; 16 between 25 – 34 years; 13 between 35 – 44 years; 11 between 45 – 54 years; and seven as 55 years or older (five missing).

Table 1. Participating groups and participants

Group type	Group name	No. of participants (male, female)
Self-advocacy	SA1 / Pilot group *	5 (3, 2)
	SA2	7 (4, 3)
	SA3	10 (5, 5)
	SA4	9 (5, 4)
	SA5	5 (2, 3)
	SA6	5 (2, 3)
	SA7	5 (4, 1)
Day Service	DS1	10 (8, 2)
	DS2	4 (2, 2)
	DS3	8 (4, 4)
College	C	5 (2, 3)
	Total	68 (38, 30)

*Included in qualitative analysis only

The qualitative part of the study involved the ten facilitators who delivered the intervention. Demographic and quantitative data were not collected from

facilitators. A pilot group and its facilitator, who ran the group with each session observed by a researcher, provided qualitative feedback which was included in the qualitative analysis. Quantitative data were not collected from this group.

2.1.1. Power analysis

In the absence of a valid measure of self-stigma in people with ID, the current study measured changes to self-esteem and mental distress given the association between these outcomes and self-stigma (Jahoda et al., 2010; Livingston & Boyd, 2010), as noted in the introduction. Furthermore, very few studies have looked at interventions aimed at reducing self-stigma, especially within ID populations. The power analysis for this study was therefore informed by prior work by Lucksted et al (2011), who piloted a nine session group intervention “Ending Self-Stigma” with adults with severe mental health problems, as this intervention informed the development of the intervention in the current study. Using the Internalised Stigma of Mental Illness (ISMI) scale (Ritsher, Otilingam, Grajales, 2003), Lucksted et al. (2011) found a reduction in self-stigma of $d = -0.57$ (medium). A power calculation was carried out using G*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007), assuming paired samples (i.e. the same participants pre- and post-intervention), specifying alpha = 5%, and desired power = 80%. The required sample was estimated at 27. However, given that Lucksted et al.’s intervention was almost twice as long as the present intervention (9 versus 4 sessions plus booster), this estimate was adjusted to an N of 50.

2.1.2. Inclusion criteria

- Participants were already accessing a group for people with ID. The decision to work with existing groups was made because familiarity with other group members and facilitators would help provide a more safe and containing environment for participants than a newly formed group. Furthermore, working with existing groups meant that a brief intervention could be delivered without the need to allow additional time for group

formation. Additionally, the research team's clinical experience suggested that forming new groups for people with ID is often beset with difficulties and attendance can be very poor due to factors such as lack of support and transport; difficulties which are far more likely to have been addressed and overcome when working with established groups.

- Participants had a mild to moderate ID, as the intervention was language-based. To ensure that participants had sufficient comprehension and language skills, discussions with group facilitators formed part of the recruitment process. To clarify the cognitive and language skills needed to access the intervention, written information and sample questions from the outcome measures were provided to all facilitators who expressed interest, followed by a phone call with a researcher to discuss this further.
- Participants were 16 years or older. Where possible, and always in the case of participants under 18 years of age, carers/supporters were informed about the group prior to participation (in some instances group facilitators said they had never been in direct contact with individuals' supporters and passing on information was left to the discretion of the respective participant).

2.1.3. Exclusion criteria

- In instances when some members of an existing group did not want to take part in the intervention, and there was no available time outside of the regular group-meeting slot in which the intervention could be run, that group did not take part in the study. This was due to concerns that group members who did not wish to take part in the study would miss out on their usual group meeting or might feel under pressure to consent to taking part.
- Existing groups did not take part in the current study if all group members did not have capacity to consent to participating in the study, again due to concerns about excluding some individuals from their group meetings.

2.2. Design

The study used a mixed-methods design. Quantitative data were collected from group members at two time points: Time 0 – at baseline, a week prior to starting the intervention; Time 1 –after completion of the booster session. Qualitative data were collected from facilitators at six time points: via written feedback after each intervention session, and via a face-to-face interview after completion of the intervention. Qualitative data were collected from group members at one time point, via a group interview immediately after the booster session.

2.3. Procedure

Participants were recruited from May to August 2017. The response rates, time scales and final recruitment were recorded. As the recruitment and retention of participants was a key research question, information pertaining to this will be presented further in the 'Results' section.

Groups were invited to complete the intervention. The groups were run by the existing group facilitators. Researchers were not involved in the delivery of the intervention, but a researcher visited each group that was recruited on three occasions: 1) to obtain informed consent and collect time 1 measures, 2) to observe session one and trouble-shoot any issues, and 3) to observe the final session, collect time 2 measures and conduct qualitative interviews.

2.3.1. Consent procedures

Participants were given information about the study in written and verbal format before they decided whether they wanted to take part. Information was initially conveyed via their group facilitators who were sent information in an accessible format to share with their group. A researcher then visited the group to go through the information sheet with potential participants and to obtain written consent (see Appendices A and B for information sheet and consent form). It was ensured that participants understood they could withdraw from the intervention at

any time. Consent was also obtained before audio-recording of the qualitative interviews.

If participants were under 18 years of age and/or were under the care of another adult (e.g. living with their parents), their carer(s) were informed about the study, see Appendix C. Regarding whether parental/carers assent or consent for the individual to participate in the group intervention was necessary, local procedures were adhered to.

2.3.2. The intervention

The Standing up for Myself (STORM) intervention (see <https://www.ucl.ac.uk/pals/storm>) under investigation drew on cognitive behavioural and narrative approaches, as these have been successfully used in other fields to boost individuals' capacity to manage and resist stigma (as reviewed by Mittal et al., 2012). It also drew on ideas and principles from liberation psychology, including the importance of acknowledging acts of oppression (Martín-Baró, 1994), which in this context include discrimination and hate crimes against people with intellectual disabilities. Peer support (people with lived experience supporting others with similar problems) available through a group intervention was an integral part of the intervention with hypothesised benefits for wellbeing and reductions in self-stigma (Pistrang et al., 2008).

The hypothesised mechanisms of action of the intervention are depicted in figure 2. In line with the constructs of stigma management and stigma resistance, as described above, the intervention used two prominent approaches for self-stigma reduction (Mittal et al., 2012): examining stigmatising beliefs and attitudes of the individual, and enhancing skills for coping with self-stigma and challenging stigmatising responses through empowerment and problem solving of positive behaviours. The intervention's strategies were derived from cognitive behavioural therapy (Beck, 1979) (e.g. challenging negative beliefs and examining the benefits and disadvantages of different ways of responding to stigma), narrative therapy (e.g.

developing new stories about oneself), liberation psychology (e.g. acknowledging acts of oppression), and peer support. As well as promoting positive outcomes, the intervention aimed to reduce the likelihood of negative outcomes resulting from carrying a stigmatising label. Negative consequences include reduced self-esteem (Jahoda et al., 2010) and lower psychological wellbeing (Ali et al., 2012). For more information on the intervention, see Appendix D for a Logic Model of STORM programme developed by the research team (Scior, personal communication).

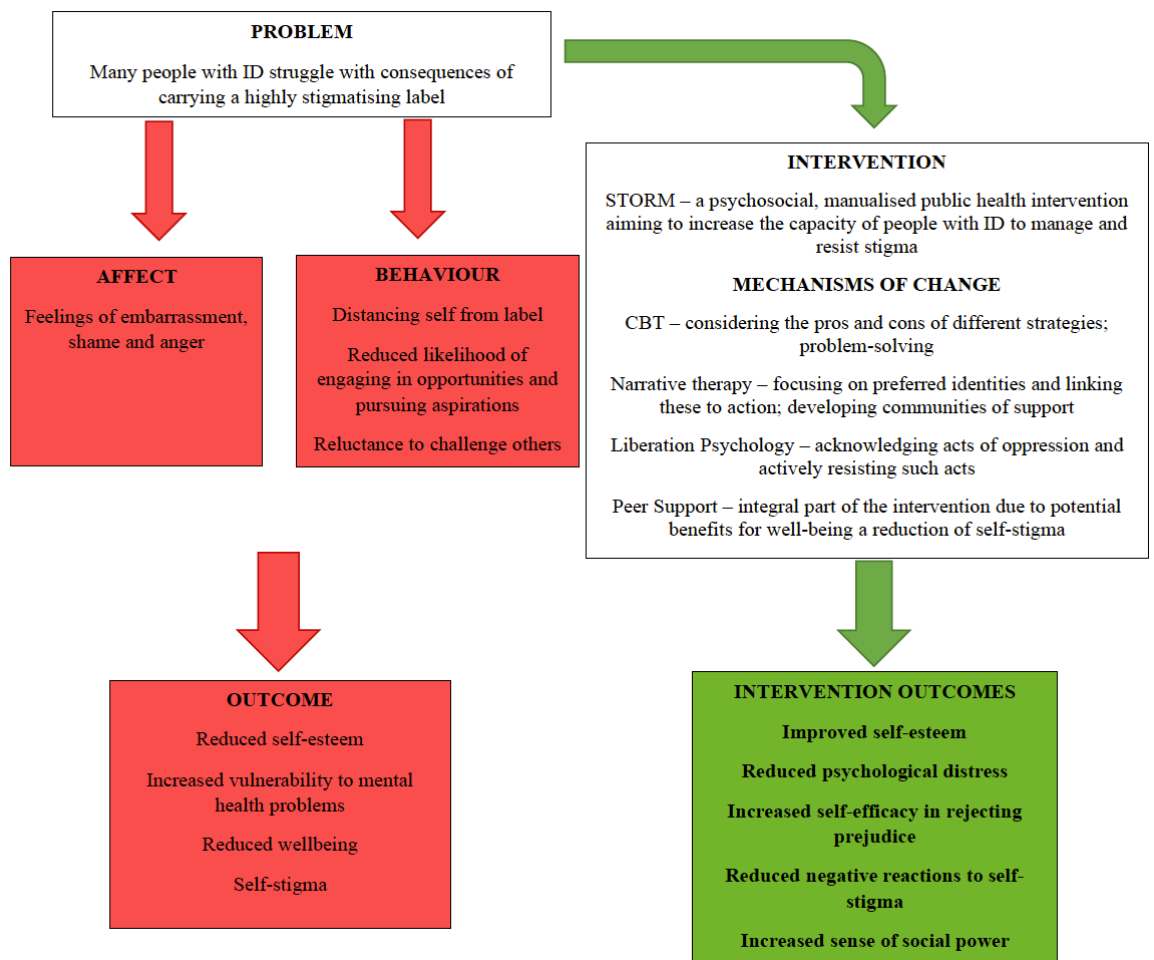


Figure 2: Hypothesised mechanisms of action of the STORM intervention;
Source: Scior (personal communication)

The intervention comprised four weekly 90 minute sessions, followed by a 60 minute booster session approximately one month after the fourth session. A summary of the five sessions and their key messages is shown in figure 3. STORM

was designed for delivery by existing group facilitators and the intervention manual and resources were created for this purpose. The manual contained introductory information for facilitators (including the aims of the intervention), guidance on how to facilitate the intervention, sessions plans and resources. A subset of the guidance for facilitators provided in the manual can be found in Appendix E. An example session plan is in Appendix F.

STORM KEY MESSAGES
Session 1 My learning disability is only one part of me.
Session 2 It's not ok for people to treat me badly. I don't have to put up with it.
Session 3 I can stand up for myself when people treat me badly.
Session 4 I can make a plan to help me stand up for myself. People I can trust can help me with ideas.
Booster Things can get in the way of my plan. Talking to others can help me decide what to do next and not give up.

Figure 3. Summary of STORM sessions and key messages

2.3.3. Development of the intervention

A national project steering group of researchers, clinicians, self-advocates with ID, and group facilitators was formed in January 2016. Under the leadership of my supervisor, this group oversaw the early phases of development of the intervention. Scoping of existing groups for people with ID across a range of sectors ascertained the perceived need for this intervention. Searches and reviews of the published literature concluded that there was no existing stigma resistance

intervention either in the intellectual disability or other fields that could be developed for the proposed purpose. However, interventions were identified that could at least partly inform the development of the new intervention.

I joined the research team during the second development phase, funded by the Baily Thomas Charitable Fund. I was involved in developing and finalising the content of the intervention, which was then presented to the project's self-advocate and group facilitator advisors to obtain feedback. Their feedback informed the version of the intervention tested in the current study. Furthermore, advice was sought from local groups of people with ID regarding the ethical implications of the intervention and what they thought potential participants needed. In line with advice on the development of complex interventions (Wight et al., 2015), such co-production maximises the likelihood of intervention effectiveness by improving, amongst other things, the fit and acceptability of the intervention with its intended recipients.

2.4. Measures and analysis

2.4.1. Self-esteem and psychological distress

In order to balance the demands of outcome measurement and group and participants' needs, abbreviated versions of several scales were used to assess the impact of the intervention on self-esteem (primary outcome) and psychological functioning (key secondary outcome). Various other exploratory outcomes were assessed (sense of power, experienced discrimination and self-stigma), but in the interests of space they are not focused on in the current report. These other outcomes were considered in a project conducted by another D.Clin.Psy trainee (Colman, 2018). See Appendix G for an outline of the other trainee's and my contributions to the joint study.

Three items from Dagnan and Sandhu's (1999) version of the Rosenberg Self-Esteem scale, adapted for use with people with ID, were administered: *I feel that I have a lot of good qualities; I am able to do things as well as other people; and*

I like myself. Participants were required to respond 'never', 'sometimes' or 'always'. Possible total scores in the current study ranged from 0 to 6, with a higher score indicating higher self-esteem. The six-item version of the scale used in Dagnan and Sandhu's (1999) study had an alpha of 0.62.

Seven items taken from the 14-item CORE-LD (Brooks et al., 2013) were administered: *Have you felt really lonely?*; *Have you had difficulty getting to sleep or staying asleep?*; *Have you threatened or shouted at someone?*; *Have you felt unhappy?*; *Have you felt people are getting at you?*; *Have you bottled up angry feelings?*; and *Have you felt really scared or frightened?*. The CORE-LD is a modified version of the CORE-OM, developed specifically to assess psychosocial functioning in people with ID . Responses relate to respondents' experiences over the preceding week, using a 3 point scale: 'never', 'sometimes' or 'always'. Possible total scores in the current study ranged from 0 to 14, with higher scores indicating higher psychological distress. There has not yet been exploration of the psychometric properties of the CORE-LD, but it is widely used in clinical practice.

See Appendix H for a copy of the questionnaire containing the Rosenberg Self-Esteem and CORE-LD questions.

Paired t-tests were used to compare pre and post intervention findings on self-esteem and psychological distress. As this was exploratory, the analysis was run on matched pre-post intervention cases only, regardless of number of STORM sessions attended. Of the 68 participants recruited to the study, 44 completed the self-esteem questions both pre- and post-intervention. The CORE-LD questions were completed by 46 participants pre- and post-intervention.

Effect sizes were calculated in line with guidance by Morris and DeShon (2008) who suggest a procedure to estimate the effect size for single-group pre- to post-test designs which takes the correlation between the pre- and post-test into account. They suggest the use of the standard deviation of the pre-test score,

because this value is not influenced by the intervention. In view of the small sample size and the risk of type 2 error, effect sizes were calculated for all outcomes.

Effect sizes were also calculated for people not already at ceiling at baseline, i.e. not showing very high self-esteem or very low psychological distress before the intervention. For the Rosenberg self-esteem measure, people who obtained the top two possible total scores (of 5 and 6) were excluded from the analysis. In the absence of any scoring guidelines for the CORE-LD measure, we used a similar rationale to guidelines for the CORE-10 (see figure in Appendix I), and viewed those in the lowest quartile as not showing distress. As the possible scoring range was 0-14, people who obtained total scores of 0-4 at baseline were excluded from the analysis.

2.4.2. Qualitative feedback from group members and facilitators

Facilitators were asked to complete written feedback after each session. They were asked to record anything that was difficult to deliver, any strong (positive or negative) reactions group members showed to the content of the session, and any other comments about delivering the session and/or group members' responses.

Two semi-structured interview schedules were developed, one for STORM participants (with ID), and one for facilitators (see Appendices J & K). The semi-structured interview schedules were developed in line with guidance (Smith et al., 2009; Smith & Osborn, 2003) and refined with input from the research supervisor following a pilot interview. They asked about participants' experiences of the intervention and its impact (positive and negative), their views on what helped or hindered implementing the intervention as planned (facilitators only), and the feasibility of administering the outcome measures and their acceptability.

The interviews with STORM participants were conducted in the form of a discussion with each group after they had finished the intervention, immediately following the booster session. All group members who took part were invited to the

discussion. Separate 1-to-1 interviews were conducted with STORM facilitators. The discussions and interviews were audio recorded with interviewees' consent. Booster sessions were also audio recorded and used as data in the qualitative analysis (details below) because the session topics included the group members feeding back on changes they had made, and therefore the potential impact of the intervention.

2.4.3. Qualitative analysis

There are different positions a researcher can take when conducting qualitative analysis. For example, an essentialist/realist stance reports the experiences, meaning and reality of the participants, while a constructionist approach looks at the way in which meanings and experiences result from a range of societal discourses (Braun & Clarke, 2006). The current study aimed to explore themes in relation to the experiences of group members receiving the intervention and experiences of facilitators delivering the intervention. An essentialist/realist method was therefore adopted. The themes were not theory-driven, but were informed by the concept of stigma resistance and the existing literature.

The qualitative data were transcribed and then analysed using framework analysis which sits within the group of thematic analysis approaches, aiming to identify and describe central ideas occurring in the data (Ritchie & Spencer, 1994). Thematic analysis approaches vary in regards to their degree of structure and interpretation they encourage (Pistrang & Barker, 2012). Along with content analysis, framework analysis compared to grounded theory or interpretative phenomenological analysis is more structured and makes more inferences during analysis.

Framework analysis was chosen as it allows a framework to result directly from the research questions and questions in the interview schedule. This was important for the current study which aimed to answer specific questions regarding the intervention's acceptability, feasibility and perceived impact. Ritchie and

Spencer's (1994) outline of the process of framework analysis was followed while analysing the data. The five key stages to the analysis are familiarisation; identifying an indexing framework; indexing; charting; mapping and interpretation.

Familiarisation. Transcripts of interviews were generated and combined with written facilitator feedback. These were then reviewed and notes were made detailing different responses and reoccurring themes.

Identifying an indexing framework. These notes, together with the research questions and interview questions, were then used to set up an indexing framework within which the qualitative data were sifted and sorted. The framework that was developed comprised ten categories within three major subject headings (acceptability, feasibility and impact), see Appendix L. The indices provided a mechanism for labelling data in manageable 'bites' for later retrieval and exploration. A common index was used for all groups and participants (group members and facilitators), to help identify both common and divergent themes. The process of devising and refining the thematic framework involved making judgements about meaning and the importance of issues.

Indexing. All the transcripts were then read and sections were indexed in line with the indexing framework. See Appendix M for an example of part of an indexed transcript. Indices were recorded on the margins of each transcript using an alpha-numerical system which linked back to the indexing framework. Single passages may have contained a number of different themes to be referenced. Multiple indexing began to highlight patterns of association within the data (Ritchie & Spencer, 1994). Indexing involved making judgements which were subjective. However, by annotating the data, the process was visible to others and to the researcher when returning to the data, making transparent how the data were being organised.

Charting. Charts were then used to show the pattern of occurrences of each index for each group, by lifting the data from the transcripts and arranging

them in relation to the relevant index. Charts were made for each key topic, and entries were made for each group (facilitator and members) on each chart. In line with Ritchie and Spencer's (1994) guidance, charting involved both abstraction and synthesis of the text. Each passage of the text, which had been annotated with a particular index, was summarised and entered on the chart. In some instances, a salient quote was entered directly onto the chart. The groups were always kept in the same order for the subject charts, so that the whole data set for each case could easily be reviewed (Ritchie & Spencer, 1994). See Appendix N for part of an example chart. This helped the researcher build up a picture of the whole data set, by looking at the range of feedback for each theme.

Mapping and interpretation. Finally, the researcher pulled together key themes in the data, mapped and interpreted the data set as a whole. The researcher returned to the research questions: what were the experiences of the participants in relation to the feasibility, acceptability, and impact of the intervention? To this end, the researcher reviewed the charts; compared and contrasted the experiences between groups; searched for patterns and connections; and sought explanations for these internally within the data (Ritchie & Spencer, 1994). This relied on the researcher weighing up the salience of issues. This process resulted in the researcher creating a framework of themes and subthemes, which is presented in the 'Results' section of the current report.

Credibility checks. Triangulation was built into the study, with facilitators interviewed separately from the group members. It was therefore possible to consider whether the same themes arose from facilitators' and group members' feedback and whether there were any clear contradictions. I considered with my supervisor whether and how to do member checks with participants. Whilst this would have been feasible, we decided there were clear indications from conducting the interviews that checking the themes would have been too complex a discussion, with a risk of acquiescence from the participants.

Researcher's perspective. Good practice guidelines in qualitative research suggest researchers should detail their perspective in terms of personal experience, training, theoretical orientations, values and expectations in relation to the area under investigation (Elliot et al., 1999). My perspective is based on working with adults and young people with ID in the field of clinical psychology. In my clinical practice, I prefer narrative and liberation psychology approaches. I value equality and justice and strive to work actively against discrimination and oppression. In research, I am mindful of the power we have as researchers to silence, speak on behalf of, or provide a platform for the voices of participants with whom we engage. I believe in hearing directly from people about their experiences. However, I am also aware of the potential power imbalances between myself (the researcher) and the participants which may influence the feedback participants gave, for example, potentially influencing participants to describe the intervention favourably.

2.5. Ethical considerations

Ethical approval was obtained from University College London's Research Ethics Committee (see Appendix O). Participants were assured of the confidentiality of their data in any analysis or publication of the results. Ethical implications included the potentially upsetting or distressing nature of discussing negative experiences and responding to measures of stigma and mental distress. On the positive side, the intervention allowed an opportunity for participants to discuss past negative experiences and concerns they may usually have found difficult to raise. The group-based nature of the intervention also meant that members had the opportunity to get support from each other and their familiar group facilitators. Feedback on the potential risk of harm was sought during the qualitative interviews.

3. Results

3.1. Recruitment and retention of participants

Ten groups were recruited to the STORM feasibility study. From May to August 2017, organisations were contacted via four methods: facilitators who had previously completed a scoping survey conducted by the research team were re-contacted; members of the research team advertised the study at a large event held by Mencap; emails were sent to organisations run for and by people with ID; and emails were sent to Special Educational Needs (SEN) schools and colleges attended by people with ID (with reference to a governmental database of schools and colleges in London and surrounding areas, i.e. the “home counties”). See figure 4 for details of the number of organisations contacted and recruited via each method.

All ten groups completed the STORM intervention. One group had a change of facilitator after two sessions of the intervention, due to the original facilitator leaving the organisation. Following recruitment, one participant dropped out of the study before attending the first session of the intervention due to other commitments. Of the remaining 67 participants, 56 (78.9%) attended at least three of the five sessions (four core sessions and the booster), and ten (14.9%) attended less than three sessions (one missing).

One participant was not included in the study as it was judged that they did not have capacity to consent to taking part, and so no data were collected from this participant. The participant remained in the group as they wished to and the group facilitator and project lead in careful discussion judged that excluding this individual from the group posed a greater risk of harm than including them.

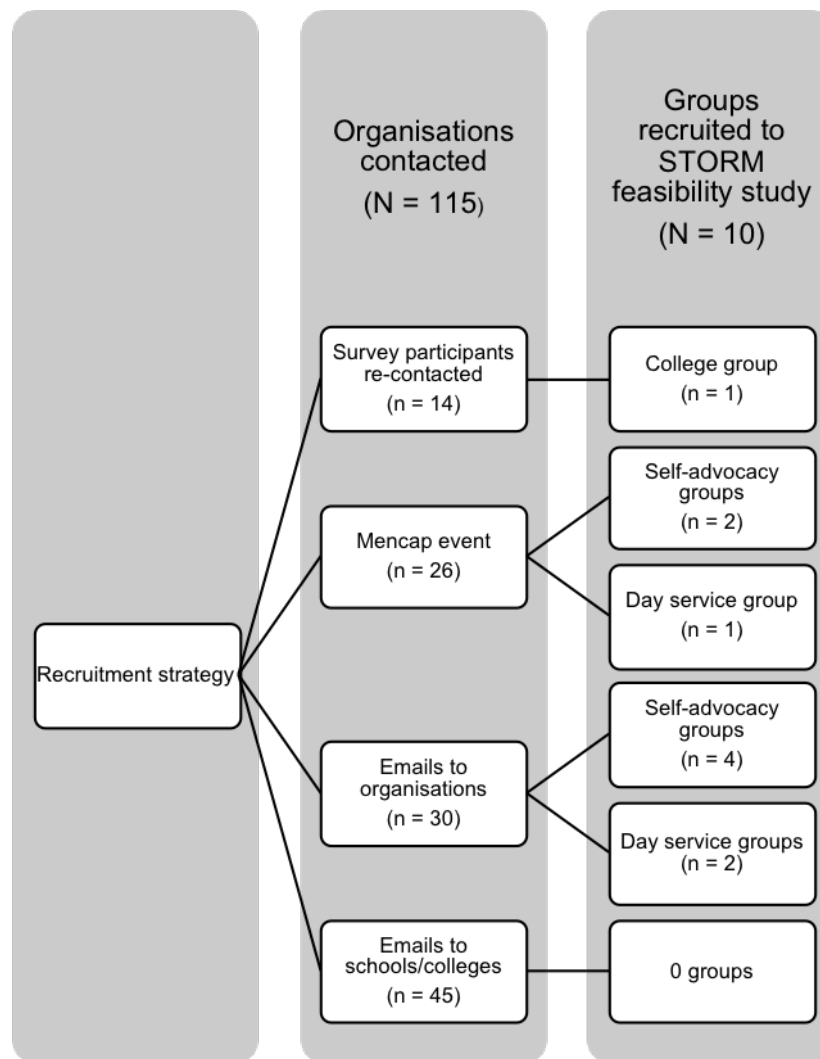


Figure 4. Recruitment process for STORM feasibility study

3.2. Quantitative results on self-esteem and psychological distress

A significant increase was found in total Rosenberg self-esteem scores from pre- ($M = 4.18$, $SD = 1.35$) to post-intervention ($M = 4.84$, $SD = 1.06$), $t(43) = 2.87$, $p = 0.006$ (two-tailed), $d = 0.43$. No significant difference was found between total scores on the CORE-LD questions from pre- ($M = 4.65$, $SD = 2.35$) to post-intervention ($M = 4.63$, $SD = 3.23$), $t(47) = 0.045$, $p = 0.964$ (two-tailed), $d = -0.16$.

Looking at participants with less than optimal self-esteem at baseline (self-esteem score <5 , $n = 35$) the effect of STORM on self-esteem was much larger, $d = 0.69$. For the CORE-LD, those showing mild or more severe psychological distress (score >4 , $n = 32$) showed a moderate reduction in distress, $d = -0.67$.

3.3. Qualitative feedback from group members and facilitators

3.3.1. Themes and subthemes

Transcripts of interviews and written facilitator feedback forms were analysed using Framework Analysis (Ritchie et al., 2003; Ritchie & Spencer, 1994). The thematic frameworks that were developed regarding feasibility, acceptability and impact are shown in tables 2, 3 and 4 respectively. A narrative report is also provided below. Experiences of the intervention were not uniform across participants, facilitators, and groups. In order to give some indication of the frequency of the occurrence of the subthemes, the number of group interviews and facilitator interviews in which each subtheme was identified are included in the thematic frameworks. The narrative report of the subthemes describes points of convergence and divergence in participants' experiences. Quotes are labelled with "GM" for group member (participant) and "F" for facilitator, followed by the type of group: "SA" for self-advocacy, "DS" for day service and "C" for college.

3.3.2. Feasibility of the intervention

Four major factors were identified that concerned feasibility: (1) manual factors; (2) facilitator factors; (3) group factors; and (4) research factors. Within these broad themes, eleven subthemes are identified (see Table 2).

Manual factors. Three subthemes were identified under this broad theme, all derived from the ten facilitators' post-session notes and interviews.

'Finding all the information needed': seven facilitators emphasised the importance of being able to find all of the information needed to deliver a session. Six of them experienced the manual as difficult to use, because information for a session was separated into different parts of the manual. For example,

I felt, with the manual, I had to keep finding bits from different places. (F, C11)

It felt like I was flicking...back and forth. (F, DS9)

Table 2. Feasibility: Thematic framework and frequency of subthemes

		Facilitator Feedback (N=10)
Manual factors	Finding all the information needed	7
	Clarity of session plans	9
	Length of the manual	5
Facilitator factors	Preparation needed	6
	Skills and confidence	6
	Number of facilitators	4
Group factors	Knowing the group	5
	Size of the group	2
	Ability of group members	3
Research factors	Support and contact at the beginning	6
	Ability to check in with a researcher	7

In contrast, one facilitator said they found it easy to find all information needed in the manual:

I found it really easy to use. I like the way it's split up into sections. It's easy to find things... Great reference tool. (F, DS10)

'Clarity of session plans': Nine facilitators cited the importance of having clear session plans. Three had found the session plans useful.

I always pulled out...the lesson plan on the day, so you could have it on the table just as an aide memoire. (F, DS10)

However, six facilitators felt the session plans could be made clearer and easier to follow.

I could have done with some bullet points – cause you go off ... and then you come back and then you are like where are you in your plan. (F, SA3)

Needs to be more idiot proof – more explicitly explained (F, DS8)

'Length of manual': Four facilitators found the manual too long, while one liked the detail of the manual.

Probably try and condense it just a bit more, because there was so much information to take in. (F, SA7)

Facilitator factors. This theme comprises three subthemes.

'Preparation needed': Six facilitators fed back on the preparation they needed to do before each session in order to deliver STORM. They reported taking up to an hour to prepare each session.

I think you should set aside at least an hour really to actually make sure you know exactly what you're doing... It got easier I have to say as sessions went on, because you almost become used to what's expected of you. (F, DS10)

'Skills and confidence': Six of the facilitators referred to the skills and confidence needed to deliver the intervention. Two spoke about skills they had which they felt would be important for future facilitators:

I've had safeguarding training. I've done a bit of reflective listening training around disclosures and things like that...I felt quite confident, but I don't know if every facilitator would in terms of having those conversations and dealing with what comes out. (F, SA1)

...whether or not the staff at (another) service would have the skills to deliver a programme like this I doubt they would, because they don't run that type of sessions...Whereas (another facilitator) and I are very used to very classroom based, very workshop based, yeah (F, DS10)

Four facilitators fed back that, at times, they felt nervous or unsure whether they were facilitating the intervention 'correctly'. For example,

I felt the entire session was difficult to deliver. Perhaps, because I felt nervous and it did not help that people turned up late. Perhaps, because I had not done it before, or I felt I did not know enough. (F, SA6)

'Number of facilitators': Four facilitators thought STORM should ideally be delivered with two facilitators present. Two of these noted challenges they encountered while delivering the intervention on their own:

I think the one thing that could have been better would be to be able to have almost two facilitators, or a facilitator and a supporter, because I think as and when there were people who needed to take a break from the room and the discussion. ..In addition, when there was a disclosure it would have been nice rather than saying let's talk about it at the end, "Would you like to step out with a supporter and go and talk about that?". (F, SA1)

Two facilitators spoke about valuing having another facilitator in the sessions:

I think it was good having X (another facilitator) there because he was able to prompt and support people he knows...I think it is probably helpful – cause you can get bogged down in a particular issue with one person having someone else there to support and cut across can help. (F, DS8)

Group factors. Looking at group factors affecting the feasibility of STORM, three subthemes were identified.

'Knowing the group': Five facilitators referred to the importance of group members knowing each other and the facilitator prior to the intervention (which was stated as a requirement in the recruitment process). Four said this was important because it helped group members talk about difficult topics.

It definitely is a plus knowing them. I think it makes it safer as well that it is somebody they do know. (F, DS9)

One facilitator spoke about the importance of knowing group members when responding to potential disclosures of abuse during the intervention:

(Following a disclosure) yeah maybe someone who doesn't have the time, or the experience, or the knowledge of who the support network is, it can be a bit problematic. (F, SA1)

'Size of group': Two facilitators spoke about being glad they had a small group (of four members):

I'm glad I had such a small group, because I was able to draw out some of their achievements. I'm not entirely sure if I would have been able to draw out some of the things with ... a bigger group. (F, SA6)

Part of it (that helped a group member talk) was the small group. We only had 4 in our group, which actually worked really well for us. (F, DS9)

'Ability of group members': Three facilitators fed back that they thought the intervention was suitable for group members with mild but not those with moderate learning disabilities.

In terms of who to deliver it to, I might have chosen some of the group slightly differently maybe. I think in terms of level of ability umm to get the most out of the programme, I think you maybe have to have a more mild learning disability to get to understand what's almost expected of you I suppose. (F, DS10)

Research factors. Two subthemes pertaining to research factors were identified.

'Support and contact at the beginning': Six facilitators spoke about the importance of the facilitator having support from a researcher at the beginning of delivering STORM, including a chance for group members to meet the researcher. For example,

It is useful to have her (researcher) there – session one was good to have (researcher) there to gauge that I was pitching it right. (F, DS8)

For me it was having someone to email – a few times before it (STORM) started to check in – and also because it (meeting researcher) makes it more real for the group ... they feel that the views are taken seriously and makes them feel listened to. (F, SA3)

'Ability to check in with researcher': Seven facilitators noted the usefulness of being able to contact a researcher if needed.

Having that ability to check in was really good... sometimes things do just fall into a bit of a grey area and you do need somebody to speak to. (F, SA1)

3.3.3. Acceptability of the intervention

Regarding the acceptability of the intervention, the thematic framework (shown in table 3) included three themes: (1) favourite aspects, (2) suggested adaptations and (3) views on upsetting nature of material. Within these three themes, eleven subthemes were identified.

Favourite aspects. Looking at what participants liked about the STORM intervention, four subthemes were identified.

'Videos': In ten (out of eleven) group interviews, participants spoke about liking the videos in the intervention, including hearing others' stories.

The videos were very moving... The videos were really interesting (GMs, SA4)

I liked yeah I saw the different videos and what I saw was that people with learning disabilities live their life to a full and even that they share their experiences of bad experiences they overcame it and kind of got on with their life. (GM, SA7)

Positive reactions to the videos were mentioned in all of the facilitator interviews, including facilitators' observations that the videos had appeared to help group members feel more confident to talk about their own lives.

I think for them to see that other people, through the videos, had been through similar journeys or not nice experiences was empowering them, so then they could talk about it. (F, DS9)

They triggered topics of conversation that the group could relate to for us to then discuss. (F, SA7)

Table 3. Acceptability: Thematic framework and frequency of subthemes

		Frequency Group interviews (/11)	Frequency Facilitators (/11)
Favourite aspects	Videos	10	11
	Activities	3	7
	Worksheets	0	4
	Doing something different	2	4
Suggested adaptations	Language used	0	4
	Reminders that writing tasks are optional	0	5
	Removal of two videos	5	10
Views on upsetting nature of material	Moved by the material	7	7
	Importance of including upsetting material	6	10
	Value of support from others	3	8
	Value of balance with positive material	0	4

'Activities': In three group interviews (each of which was a self-advocacy group) and seven facilitator interviews the STORM activities were talked about positively, particularly activities focused on how to respond to negative treatment and action planning. For example:

I liked the whole thing like the action plans interesting. The things we've got to do on the action plans are very interesting. (GM, SA4)

Lots of positive ideas on useful tools to help themselves and where to seek help if required (F, DS9)

They were very happy to plan and set goals and targets to work towards. (F, SA7)

'Worksheets': Four facilitators commented positively on some of the worksheets provided as part of the STORM manual, noting in particular that some group members liked keeping notes on what they had done.

There was one for notes that they could have each week as a diary. (F, SA2)

Particularly the group here, like to have evidence themselves of what they're involved in. (F, SA5)

'Doing something different': Two of the group interviews and four facilitators said they liked that the intervention meant they were doing something different to the usual.

I liked about STORM we looked at different kind of stuff and we learnt skills.

We learnt different kind of new skills (GM, SA1)

It was different, hard work, a lot of thinking, interesting... it got our brains going. (GMs, SA3)

And just the enthusiasm to learn and to do something different that's what I liked about it. It was just great for the guys, really good. (F, SA10)

Suggested adaptations. Three subthemes summarise what participants did not like about the STORM intervention.

'Language used': Four facilitators thought some of the language used in the intervention was not accessible to group members and needed adapting or further explanation.

(When asked what they did not like): Oh and some of the jargon words as well like... "achievements" and being "embarrassed". (F, SA1)

Sometimes we took the words apart and explained things in more simplistic terms. For example the word prejudice had to be explained. (F, DS8)

'Reminders that writing tasks are optional': Five facilitators commented that many worksheets were inappropriate.

I felt the handouts did not work. There were too many of them and too difficult, wordy or uninspiring for this group. (F, SA6)

Writing tasks and worksheets were presented as optional in the manual with instruction that facilitators use their discretion in ensuring any writing fits with participants' needs. The feedback suggests it should be stressing even more strongly that any writing tasks are optional and their use should be carefully considered in advance.

'Removal of two videos': Five group interviews and ten facilitators fed back that two videos in particular should be removed from the intervention. One video had caused offence to participants in one group, because of the language used. The other videos included regional accents which participants found difficult to understand.

Views on upsetting nature of material. The interviews included specific questions about any negative impact of STORM, including the potentially upsetting nature of some of the videos and topics. Four subthemes were identified.

'Upset by material': That some of the material was upsetting to participants was reported in seven group and seven facilitator interviews.

I think a lot of it made a lot of people feel upset...I was crying. (GMs, SA4)

The first video was quite hard hitting and group were visibly shocked by what was said. (F, DS10)

One facilitator (College) highlighted the importance of remembering that facilitators and other support staff may also be upset by the material.

'Importance of including upsetting material': Six groups and ten facilitators fed back that, even if at times it was upsetting, it was important for participants to have the space to view and discuss such material.

I do think it's important to keep it in and not take it out, because it may upset some people in the aspect that everybody has the right to feel different emotions, but the thing is if you take it out it's going to take away the message. (GMs, SA7)

I think quite a few of the group actually found (video of bullying on bus) quite shocking and really difficult, but at the same time I think it's vital we do have these conversations, because it's the reality. (F, SA1)

'Value of support from others': The importance of support from others when upset by some of the material was identified in three group and eight facilitator interviews.

If worried after session, can talk to staff...safeguarding officer...facilitator...family. (GMs, College)

The STORM idea of having not to continue and if it is somebody you know it was to become too much for one person, you would then follow that up...when talking about negative experiences we took a little time to ensure everyone was feeling ok (F, DS9)

'Value of balance with positive material': Four facilitators spoke about the value of the balance of positive and negative material, which was built into the intervention and reflected throughout the manual.

Always end on a happy note this session (two) as it can bring up a lot of bad memories or things that make the members feel a bit down. (F, SA2)

It was good to finish on a positive after discussing the sad things in the group. (F, SA4)

3.3.4. Impact of the intervention

Finally, regarding participants' experiences of the impact of the STORM intervention, the thematic framework (see table 4) included three major themes: (1) enhanced stigma resistance; (2) other positive effects and (4) moderators of effects. Within these three themes, ten subthemes were classified.

Positive: Enhanced stigma resistance. Considering the intervention's positive impact on stigma resistance, five subthemes were identified.

Table 4. Impact: Thematic framework and frequency of subthemes

		Frequency Group interviews (N=11)	Frequency Facilitators (N=11)
Enhanced stigma resistance	Acknowledging acts of oppression	7	8
	Affirmations of stigma resistance	8	2
	Plans to resist stigma	7	7
	Plans to educate others	5	3
	Empowerment and confidence	6	5
Other positive effects	Acknowledging strengths and achievements	1	4
	Improved relationships	10	9
	Learning new facilitation skills	n/a	4
Moderators of effects	Prior involvement in stigma resistance	6	4
	Stigma not seen as an issue	0	2

‘Acknowledging acts of oppression’: STORM providing space for this was identified in seven group and eight facilitators interviews.

I think sharing (bad experiences) with somebody else is a good thing, because the saying “a problem shared is a problem halved” or something, so it’s good to talk about, because if you keep it all to yourself it just eats away at you. (GM, SA1)

My experience I spoke about was how my family have always thought of me as disabled, so they’ve always made me think you can’t do what you want to do ... And for me that made me feel, “I’m just disabled. I can’t do nothing.” (GM, SA7)

We had conversations about 'controlling behaviour' by someone who is generally nice and kind but wants to control you and whether this is bullying. We decided it was. (F, SA5)

'Affirmations of stigma resistance': Statements or assertions in line with stigma resistance were identified in eight of the group and two of the facilitator interviews.

Now I think, "why should I be intimidated?" (GM, SA6)

We're all different aren't we. We're all individual. (GM, DS8)

(Group members) like having that responsibility. I think "standing up for yourself" it's putting it back on them. It's not always telling someone to sort it out. Actually, I can do something. What can I do? I can be strong. (F, College)

'Plans to resist stigma': Plans to resist stigma were spoken about in seven of the group and seven facilitator interviews.

Mine (action plan) is speaking up about what is important to me and talk and get together a group, and meet people with a disability. (GM, SA2)

Two of the participants wanted to start their own self-advocacy type group and that's starting up next month. (F, DS9).

'Plans to educate others': Plans to educate other people were identified in five group and three facilitator interviews.

...tell people without a disability what it's like to have a disability...want to organise a learning disability awareness event. (GMs, SA2)

Some of us are going to (give) a talk in schools. (GM, DS10)

'Empowerment and confidence': Feedback suggesting increased empowerment and confidence was given by six groups and five facilitators.

It really inspired me a lot to be more confident and to help people like me as well. (GM, SA7)

Quite empowering for them and for me. (F, DS9)

Other positive effects. Three factors related to experiences of other positive effects.

'Acknowledging strengths and achievements': One day service group fed back on the positive impact of acknowledging strengths and achievements. Facilitators from all three of the day service groups also identified this positive impact, as did one facilitator from a self-advocacy group.

Well we shared what we're capable of. (GM, DS10)

Do you know what the best part for me was?..sometimes it's really good to be reminded of how able and capable our guys are and...it just gives me a bit of a kick up the bum and actually don't underestimate anybody (F, DS10)

I got to know (group members) a lot better, saw a different. Thinking of one of the male participants, someone who would come across quite quiet and not bothered about stuff, was actually quite a passionate, independent young man who actually had lots to say and when he was given the opportunity and the forum to do so he did. (F, DS9)

'Improved relationships': Improved relationships was identified as a positive impact of STORM in ten group interviews and nine facilitator interviews, across all three types of group.

We've learnt new stuff, about each other (GM, SA2)

Meeting much more regularly...so people actually had the chance to get to know each other a bit more and...by the end of it I felt they were strong bonded as a group...and that they were kind of more looking out for each other in some ways. (F, SA5)

'Learning new facilitation skills': Four facilitators said STORM had allowed them to develop new facilitation skills.

As a facilitator, to see how you guys have built the programme and having like the check-in, having the reminder points like each session having a clear

message, that gave me a lot of almost like a mini-training and bit more experience of my facilitating skills. (F, SA1)

Moderators of effects. Two subthemes were identified under this theme.

‘Prior involvement in stigma resistance’: In six group and four facilitator interviews, participants spoke about group members’ involvement in stigma resistance prior to the STORM intervention, as a part of their self-advocacy work.

We train the banks to understand people’s learning disabilities and we’ve also trained the ambulance and the paramedics. (GM, SA4)

I think if you had a group that wasn’t used to speaking up it could give them the tools for this. But for my group it was providing us with a safe space to think about these issues again. (F, SA2)

‘Stigma not seen as an issue’: Two facilitators from day service groups felt that stigma may not be an issue for their group members.

(Some group members) do not have the self-consciousness and I do not want to do a disservice – I don’t think there is a huge conscious awareness that people are discriminated about. (F, DS8).

I know they did share some not nice experiences, but the community they live in is quite accepting, quite safe, quite a lovely place to live in, so I don’t know if things have been made better. (F, DS9)

4. Discussion

4.1. Summary of results

Encouraging results were obtained in the current feasibility study. The desired number of participants was recruited within the designated timeframe and they were retained throughout the study. Initial quantitative assessment of the effects of the intervention indicated a small increase in self-esteem and a small reduction in psychological distress. Qualitative assessment found that factors relating to the intervention manual, facilitators, group members who received the intervention and support provided by the research team impacted on the feasibility

of delivering the intervention. Feedback on participants' favourite aspects of the intervention suggested that participants liked the videos, activities, worksheets and doing something different. Suggested adaptations included some of the language used, reminders that writing tasks are optional, and removal of specific videos. Feedback that was sought about the upsetting nature of the materials suggested that, whilst some participants were upset, they emphasised the importance of including the upsetting material in the intervention. The feedback highlighted that support for participants was managed well by facilitators, as instructed in the intervention manual, as was the balance between upsetting and positive material that was built into the intervention. Feedback on the perceived impact of the intervention suggested that enhanced stigma resistance was a positive effect, operationalised as acknowledging acts of oppression, affirmations of stigma resistance, plans to resist stigma and educate others, empowerment and confidence. Other positive effects were acknowledging the strengths and achievements of group members, improved relationships in the group and opportunities for facilitators to learn new skills. There seemed to be less of an impact on stigma resistance for groups that were already actively involved in resisting stigma as a part of their self-advocacy (e.g. speaking up for their rights and educating others), and where facilitators thought that stigma was not an issue for their group members.

4.2. Limitations of the current study

Both the quantitative and qualitative data collection was potentially limited in the current study. Enhancing the capacity of people with ID to manage and resist is a key aim of the intervention. However, there is not validated measure of self-stigma in people with ID, so it was not possible to measure this directly. The associated outcomes of self-esteem and psychological distress were therefore measured.

The qualitative interviews were conducted by myself, and it is possible that participants' knowledge that I was involved in the development of the intervention may have influenced them to evaluate the intervention more favourably and to withhold negative feedback. I have also wondered about the position I held as someone not carrying the label of an intellectual disability diagnosis, and whether this impacted on the interview context and if it affected the feedback obtained. I have wondered whether I could have conducted the data collection in alternative ways, for example by facilitating participants to interview each other in the form of a more informal conversation, or whether participants could have been interviewed by their usual group facilitators.

Furthermore, my involvement in the development of the intervention, and my knowledge of existing literature, could have introduced bias into my analysis of the qualitative feedback. Although steps were used to limit this bias, including the use of a semi-structured interview guide and transparency in the steps of the qualitative analysis, it is unlikely that bias was entirely removed.

4.3. Implications for future research into STORM

In line with MRC guidance (2008), the results of the current feasibility study help to inform future development and evaluation of the STORM intervention. Firstly, both the quantitative and qualitative results suggest positive effects of the intervention and therefore that it is a worthwhile endeavour to continue its development and proceed to a controlled trial (further discussion of the clinical implications below). Secondly, the prompt recruitment and high retention rates of participants suggest that there is both an appetite for the intervention amongst target groups and that future recruitment will be feasible. Thirdly, the detailed feedback from participants suggests specific and achievable adaptations to the intervention before it is delivered as part of a controlled trial. For example, it is suggested that the material included in the intervention manual be condensed in order to reduce its length and certain language be changed. Finally, experiences of

conducting the current feasibility study can help inform the design of future evaluations. For example, the current quantitative analysis included all matched pairs of responses (pre to post intervention). However, there are other important factors that may have influenced the impact of the intervention that were not captured in the analysis including dosage (i.e. number of sessions attended), group size and organisation type.

4.4. Implications in the context of the stigma resistance literature

Development of the STORM intervention and the current feasibility study were based on the assumption that people with ID need support developing stigma resistance, without detailed consideration of the concept of stigma resistance. Recent publications by Firmin and colleagues (2017) have sought to unpick the concept, focusing on the field of stigma in people with mental health problems. Using qualitative analysis of interviews with people with serious mental health problems, Firmin et al. (2017) developed a framework of stigma resistance which conceptualises it as a multifaceted and ongoing process operating at the personal, peer and public level. They also concluded that there is a need for interventions to focus on increasing stigma resistance

Although a model of stigma resistance has not been developed specifically in the field of ID, it is possible to map the qualitative results of the current study regarding enhanced stigma resistance onto the framework developed by Firmin et al. (2017). At the personal level, participants of the current study vocalised beliefs in line with stigma resistance, such as having equal rights and not believing the negative judgments of other people. Additionally, Firmin et al. (2017) discuss personal empowerment through learning, including learning about the effects of stigma; participants in the current study similarly spoke about the importance of acknowledging acts of oppression and discrimination. At the peer level, participants in the study by Firmin et al. spoke about the connection they felt with others with shared lived experience. Participants in the current study spoke about the

importance of hearing each other's experiences and the stories told by people with ID in the videos. Finally, at the public level, the model developed by Firmin et al. includes educating others and challenging stigma. Participants in the current study fed back their plans to educate other people such as school children and health professionals about ID. They also shared plans to speak out against discrimination.

Considering the broader context of countering stigma against people with ID, it is important to remember the different levels at which interventions can be targeted, as described by Scior & Werner (2016) in their multi-level model of stigma change interventions. Whilst STORM aims to target self-stigma at the intrapersonal level, other interventions are needed to address stigma at the structural level, interpersonal and familial levels. For example, through greater representation of people with ID in the mass media, reduction of hate crimes, and addressing stigma among children with ID and their peers at school (Scior & Werner, 2016)

4.5. Other clinical implications and conclusion

The results indicate other ways in which the intervention may benefit participants, with similarities and differences between groups. Among factors relating to the perceived impact of STORM, the subtheme that was reported by the highest number of participants (both facilitators and group members) was improved relationships within the group. This result supports the importance of peer support, a therapeutic paradigm which is utilised in STORM and which is gaining increasing attention, particularly in the field of mental health (e.g. Puschner, 2018).

A positive effect of STORM reported particularly by facilitators of day service groups (as opposed to self-advocacy groups), was the opportunity to acknowledge the strengths and achievements of group members. Opportunities to appreciate the strengths of people with ID can be considered an important way of "proving stigma wrong" (Firmin et al., 2017, p1). It is interesting to note that this positive effect was not fed back by facilitators of self-advocacy groups, and one could argue that recognising the strengths of members is already an intrinsic part of self-advocacy.

Furthermore, less of an impact was perceived by some self-advocacy groups who noted that they were already involved in many acts of stigma resistance. Results such as these suggest it is possible that the research literature and evidence base on stigma resistance in ID is only now beginning to catch up with the important work that self-advocacy groups have been doing for several decades. Indeed, a key factor justifying the continued development and evaluation of STORM may be to encourage people with ID who are not already accessing self-advocacy groups to do so, and indeed for them to create new opportunities, form new groups and in turn to educate researchers on what stigma resistance in people with ID is and how it is lived.

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Part 3: Critical Appraisal

1. Introduction

This report offers some critical reflections on the study outlined in Part 2 of the submitted thesis which assessed the feasibility of a new psychosocial intervention designed to increase the capacity of people with intellectual disabilities to manage and resist stigma. In this report, I use various ideas and practices from systemic therapy to help critically reflect on the research process I undertook. I will first consider how the research, as a whole, relates to a growing awareness of the professional values I wish to uphold, including ideas from Liberation Psychology (Martín-Baró, 1994), such as acknowledging the social and political context of clinical psychologists' work and privileging the perspectives of the people whom psychosocial interventions aim to help. Next, I consider the collaboration with self-advocate advisors in the research team and use an outsider witness practice (White, 1995) to reflect in detail on a moment of learning. I then discuss how aspects from the work tie with ideas from 'Scholar Activism', which argues for academic work to pursue social justice (e.g. Kagan, 2017). Finally, I use the Coordinated Management of Meaning framework (e.g. Cronen & Pearce, 1985; Pearce, 1994) to consider the levels of context affecting the qualitative interviews conducted and the resulting feedback obtained.

2. My professional values and the research

Whilst conducting this research, a process I have found interesting is the development of my skills as a researcher within my professional development as a clinical psychologist and a growing understanding of the values I wish to uphold. For example, I believe in the value of collaboration with others and transparency in research and clinical processes. Other ideas that resonate with me are that therapists are changed by their work with people and what they learn from them (e.g. Walther & Fox, 2012; White, 1995) and that people are the experts in their own lives (e.g. Morgan, 2000). Furthermore, I strongly believe that therapy is inherently

a political act in the sense that, "The personal is political" (Hanisch, 2000, p113) which necessitates reflection on one's ethical stance (Besley, 2002).

From both the teaching I have received and clinical experience I have accumulated whilst on placement, I have become increasingly interested in the practices of Liberation Psychology, which aims to develop and re-work psychological theories and concepts using the perspectives of oppressed and marginalised communities (Martín-Baró, 1994). The STORM intervention, the feasibility of which I was assessing, drew on ideas within Liberation Psychology as well as a number of other therapeutic models. In the context of stigma against people with intellectual disabilities (ID), people carrying this label are marginalised by stigmatising forces including direct hate crime, prejudice and systems which benefit people who do not carry the label. The intervention recognised acknowledging acts of oppression as an important first step in addressing and resisting stigma. This focus is consistent with Freire's (1998) concept of 'conscientization', or consciousness raising, which emphasises the importance of raising people's awareness of oppressing social forces in order to be able to change these forces.

As well as the explicit inclusion of Liberation Psychology ideas within the intervention, I was also drawn to this research project for its use of qualitative methodology to gain feedback on the intervention from participants themselves. For me, this style of research fits with the Liberation Psychology ideal of privileging the perspectives of those people who are oppressed in social systems and striving for psychological understandings that speak to their experience (Burton, 2013). The project centralised the feedback and ideas of people with ID in order to develop and evaluate the intervention rather than designing the intervention purely using a top-down process.

3. Collaboration with self-advocate advisors

As well as the central role of people with ID in the evaluation of STORM, self-advocate advisors with ID were involved at many stages in the development of STORM (details of involvement are in Part 2 of the current thesis). Efforts were made by the research team to ensure that self-advocates genuinely had opportunities to influence the programme along with other researchers and that their involvement was genuine collaboration and not “tokenism” (Roberts et al., 2012). There is also a wider shift in discourse in research to participatory action research (e.g. Baum et al., 2006), co-production (e.g. Dowse, 2009), and peer-peer support (e.g. Puschner, 2018). These three approaches to research and clinical practice share the quality of researchers and clinicians moving away from an ‘expert’ position. Furthermore, when published, the latter article was the most read article in the high impact journal “Epidemiology and Psychiatric Sciences’ (Scior, personal communication), suggesting there is a huge appetite for this work when it is given a platform.

I am grateful to have worked as part of such a large research team comprising people with different experiences, as doing so gave me many opportunities to learn from other people. Both to help bring to life these moments of learning and to aid my reflection on their meaning, I will focus in on one particular interaction and use an outsider witness practice (White, 1995). Outsider witnessing is a practice used in systemic therapy to listen, respond, and acknowledge the preferred accounts of people’s lives (Walther & Fox, 2012). I will follow the framework of noting the verbal expressions that stood out to me, the image this evoked, the personal resonance and to where it transported me (White, 1995). During a meeting with one of the self-advocate advisors about disseminating the research on STORM at an upcoming conference, we were talking about how he would like to describe the self-advocate advisors’ roles in the research. He wanted to speak about teaching the researchers that information should always be

accessible, for example taking out “jargon” words. He then likened it to providing an alternative, jargon-free product, akin to having gluten-free and sugar-free products at the supermarket (Roche, personal communication). I was struck by this expression and it immediately created the image in my mind of a supermarket shelf with different options and each person choosing the product that was right for them. Indeed, the advisor then went on to describe that image and say that we could include it in the presentation. I think this expression and the related image resonated with me, because it reminded me of the everyday act of going to the supermarket which connected with how it should be very usual and expected that different requirements (e.g. having accessible information) are catered for. In that meeting we noted how excited we felt to share this analogy with others at the conference and pleased that it incorporated some humour into our presentation. I will also carry this analogy with me to future situations in my work as a clinical psychologist.

4. Ideas from Scholar Activism

Conducting research in the field of stigma, which includes social forces at many levels of society, I have found it interesting to read about ideas of ‘scholar activism’, which argues for academic work to pursue social justice, requiring critical reflection and strategic alliances (e.g. Kagan, 2017). The development of the STORM intervention is an engagement in scholar activism in the sense that it was aimed at the betterment of the social situation of people with ID through bringing to light stigmatising forces and increasing stigma resistance. Furthermore, Derickson and Routledge propose a ‘politics of resourcefulness’ (2015, p2) as a framework for researchers who wish to engage in scholar activism, which includes a commitment to using resources held by academics (e.g. access to technology and experience in grant writing) to advance the work of non-academic collaborators (e.g. community groups). Consistent with this framework, the current project has highlighted the important and effective work of existing ID self-advocacy groups.

5. Levels of context and the qualitative interviews

The current thesis was the first time I have undertaken qualitative research and I appreciated developing these skills. Something that surprised me during the data collection phase, were reminders that I was working as part of, and therefore representing, UCL, which is a large and influential organisation. This became particularly apparent to me when collecting outcome measures and conducting interviews with groups who had finished running the STORM programme. Several participants commented that they were grateful that UCL wanted to hear what they thought. For example, one facilitator commented:

I think it is really nice that you have come out and asked people's views... they feel that the views are taken seriously and makes them feel listened to.

I found these comments humbling and contrary to what I had expected, which were perceptions that I was encroaching on people's time and adding demands on top of their usual activities. I also felt a dissonance between the views that I represent UCL and my experience of being both an unqualified, trainee psychologist and relatively new to the world of research.

I have since wondered how the different aspects of my context impacted on the atmosphere I co-created with the participants during the qualitative interviews. I have found the Coordinate Management of Meaning (CMM; e.g. Cronen & Pearce, 1985; Pearce, 1994) to be a useful framework to help me reflect on these interactions. CMM explores how meanings and actions emerge within different levels of context. It considers how social forces affect individual experience and vice versa (Afuape & Hughes, 2015).

At the contextual level of what was said during the interview, I was heavily (and intentionally) influenced by the interview structure I had developed beforehand. The use of this structure was to ensure that what I asked covered the various research questions and that there was some consistency between interviews. To try to make this process transparent to the participants, I let them know at the

beginning of the interview that I had some questions written down that I wanted to ask them. Something I did not enquire about was participants' previous experience of being interviewed in this way. Previous experiences of having conversations with a new person may have affected how participants felt during the interviews and that in turn may have impacted on the content of their answers. In order to reflect on the whether the meanings I was communicating in the interviews were closely related to those I intended, I listened back to recordings early on in the data collection. This helped me to refine my style of questioning. For example, in order to communicate more strongly my curiosity about participants' experiences, I decided to emphasise that there were no right or wrong answers and that whatever participants thought was what I wanted to hear. Furthermore, some group interviews were conducted together with another researcher. The benefits of this were having an observer who noticed additional aspects during the interviews and the opportunity to reflect together afterwards.

In terms of the episode within which the interviews took place, I hope the familiarity of the usual group meeting (time, people and place) helped participants to feel relaxed and comfortable, which I assumed would help them feel able to give honest and open feedback regarding their experiences of the programme. Additionally, I strove to be as responsive as possible to the participants' needs. For example, I ensured we had a lunch break at a time that suited them and more frequent breaks if necessary (both agreed at the start of the interview and in response to participants either looking tired or saying they needed a break).

I have wondered how both the participants' and my identity and previous life experiences impacted on the interview context. I found it useful when participants provided information about their lives when describing their experience of the intervention, as it helped me to contextualise their experiences and the impact of the intervention. For example, one participant explained that she felt she had benefited

from the intervention, but also spoke about her previous involvement in similar programmes:

I've been doing this project for 3 years: the disability hate and mate crime project. It has really inspired me and opened my eyes to understand the signs and risk of people trying to pretend to be my friend and not being genuine.

In terms of the relationships I built with the participants during the interviews, I have hoped that my clinical and therapeutic skills helped the development of rapport with participants. However, I have also noted my position as a researcher rather than a clinician during the interviews. For instance, I found myself re-directing people back the research questions whereas I would usually be more client-led in therapeutic conversations.

Other contexts considered within the CMM framework (family, cultural, spiritual, and political) were sometimes explicitly talked about by some of the participants. When participants discussed these contexts, it helped me understand how they related to the intervention and the resources they drew upon. For example, one participant spoke about stigmatising attitudes and how they related to her religious beliefs:

Just 'cause we have disabilities doesn't mean we are not people. We have spirit and soul. It (an intellectual disability diagnosis) doesn't mean you are possessed by demons. All I see and feel is good and I have God's love and angels' love.

It seems particularly pertinent to me now that I did not specifically ask about these levels of context, but this was a conscious decision due to both the limited time available and prioritisation of research questions. Nonetheless, doing so may have yielded rich information and further contextualised participants' feedback.

The above levels of context would have also impacted on the facilitator feedback I obtained. In particular, I noted some differences between feedback from facilitators which appeared to be affected by differences in their professional identity, experience of being involved in research, and how they related to the intervention. For example, some facilitators questioned their own facilitation skills, and some fed back that they had, at times, adhered to the intervention manual even though they had wanted to adapt it, because they had not wanted to affect the results of the research. Other facilitators used the programme as much as they found useful and appeared more comfortable omitting parts they did not think would be helpful for their group. This feedback was very useful in considering the feasibility of the intervention and factors that affected its implementation. Again, if there had been time, conversations around other contexts (e.g. political, cultural) may have yielded further useful information to inform the intervention's future development and evaluation.

6. Conclusion

The practice and dissemination of applied research is an important aspect of clinical psychology. As I come to the end of my training, the approaches and ideas I have reviewed in this report are ones that speak to my beliefs in collaboration and social justice. The current thesis has been a valuable opportunity to consider how these ideas can be practiced and upheld. I have learnt that it requires a balance of drawing on existing theories and knowledge, collaborating with others, constantly reflecting on current practices and disseminating your work in order to inform and shape these systems.

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Appendix A
Information Sheet



You can ask someone you know to help you read this letter.

We are the research team:



Katrina



Lisa



Sophini



Kristina



Sophie



We are doing research with University College London.



Research means finding out about things.



We are doing research to find out the effect of a new group programme for people with learning disabilities.



Standing up for myself

The group programme is called Standing up for Myself (STORM).



We would like you to take part in this research.



This letter will give you information about the research and what we will ask you to do if you want to take part.



You can talk about it with other people like your family and friends if you want.

Why we are doing this research



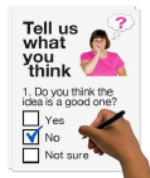
Some people with learning disabilities feel bad because of other people's views of learning disability.



We developed a new group programme for people with learning disabilities to help them to cope with this.



We want to try out the new programme to see if it works.



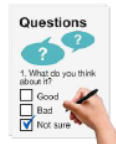
The research will help us understand if it works well.

We are asking you to take part



We are asking you if you want to take part because you attend a group for people with learning disabilities.

About the research



We will ask you to answer some questions about you and how you feel.



You will meet for 4 weeks with your group.

There will be a booster session after one month.



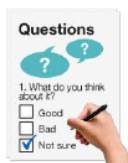
Each meeting will last 1 hour 30 minutes.



Each week the group will talk about different topics.



The group will talk about things like personal experiences of coping and videos about other people's experiences.



When the meetings have finished, we will ask you to answer some questions about how you feel.

Choosing to take part in research



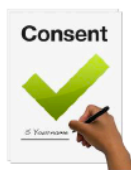
You can choose if you want to take part in the research.

It's up to you.



You can say no.

If you say no to the research, you won't be treated any differently.



If you say yes to the research, we will ask you to sign a consent form.

This consent form says that you agree to part in the research.

Changing your decision



You can stop taking part in the research at any time.

You don't have to tell us why.



You can tell us to destroy any information that we have about you.

What we do with your answers



Your answers will be confidential.

That means we don't share it with anyone.



Only the research team will see your answers.

Where we keep your answers



We will keep your answers in a locked place.



Your name will not be on the answers.



When we have finished the research, we let you know what the research found.

We will not use your name in our report.

Good things about taking part



You might learn something new from taking part in the group meetings.



What you say may help other people in the group.



What we find through the research might help other people with learning disabilities.

Things that might be difficult



Some questions might be difficult or make you feel sad.



We will make sure that there is someone to talk to about anything you found difficult or sad.



You can stop taking part in the research at any time.

How to make a complaint



If there is a problem, you can talk to your group leader first. They will try and help.



If you are still unhappy, you should talk to someone from our research team.



You can contact Katrina Scior:



E-mail: k.scior@ucl.ac.uk

Phone: 0207 679 1845



We will do our best to sort out the problem.

We will tell you when we think the problem has been fixed.

Appendix B
Consent form

Please tick the box if your answer is 'Yes'.



1. Have you read the information letter or has it been read to you?



2. Do you understand what the project is about?



3. Do you understand the good things about taking part?



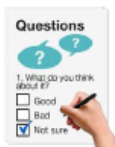
4. Do you understand what might be difficult about taking part?



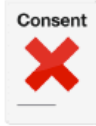
5. Have you asked all the questions you want?



6. Were your questions answered in a way you understand?



7. Do you understand that your answers will be written down?



8. Do you understand that it is OK to stop at any time?



9. Have you had time to think about if you want to take part?



10. Are you happy to take part?



If you want to take part, please sign below:

Name: _____



Signature: _____

Date: _____



If you don't want to take part, you don't have to sign.

The researcher will complete this section:

Researcher's Name: _____

Signature: _____ Date: _____

Appendix C

Carer Information Sheet

Dear Family/Supporter of _____,

As a family member or someone who supports _____ we are writing to let you know that they have agreed to take part in a group programme called Standing Up for Myself (STORM). The group programme will be run by a trained facilitator at _____ (*name of group*) over 5 sessions. The sessions will run on _____ (*day*) at _____ (*time and place*).

In order to understand the impact of the group programme for those attending, we want to collect some information from people through a questionnaire. There will be a further 2 sessions with the group which will be attended by a member of the University College London (UCL) research team. At these sessions the researcher will support people to complete a questionnaire.

We have enclosed more information about the group programme and the related research study with this letter.

If you have any questions or comments about the group programme you can contact:

_____ (*facilitator name*)

If you want to contact the research team directly, our details are at the bottom of this letter.

Kind Regards,

Katrina Scior, Lisa Richardson and Sophini Logeswaran

Contact details: Should you have any queries or require any further information, please do not hesitate to contact Katrina Scior (Project Lead):

Tel- 02076 791 845

Email- k.scior@ucl.ac.uk

Background- why we are doing running these programmes and the research:

- People with learning disabilities face negative feelings and experiences because of the way they can be viewed by others. Despite positive changes in policies, services and societal views, negative attitudes and discrimination remain everyday realities for many people with learning disabilities.
- Despite a clear need to do more to empower people with learning disabilities to manage such feelings and experiences, to date few interventions have targeted this and none have been shown to be effective.
- Having better ways of coping in people with learning disabilities is likely to have positive effects on their mental health, well-being and social interactions.

Who are we?

- We are a team of researchers from University College London (UCL). The team includes researchers, clinicians and self-advocates with learning disabilities from different parts of the UK.
- Our research aims to advance our understanding of the lives of people with learning disabilities, in particular how people experience and can cope with negative attitudes and behaviours towards them because of their learning disability.

About the research study

- The current project is funded by the Baily Thomas Charitable Fund.
- We have developed a new group programme called **Standing Up for Myself (STORM)**, to help people with learning disabilities cope with and stand up to the bad attitudes and behaviours they often have to face on account of having a learning disability.
- We would now like to find out how manageable it is for existing groups to run this programme and to see what impact it has for people with learning disabilities.
- In the future we hope that this programme will be a freely available resource that group facilitators can use with groups when they feel is useful for them.

Standing Up for Myself (STORM) Programme

- STORM is a 4-session group programme (plus 1 booster session) which consists of filmed first-hand testimonials by people with learning disabilities, discussions and practical exercises.
- It is designed to be interactive, thought-provoking and fun, despite the serious topic.

The themes of the four sessions are:

- 1) What does 'learning disability' mean to people with learning disabilities? What does it mean to me?
- 2) How are people with learning disabilities treated by others?
- 3) How do people with learning disabilities respond to negative treatment from others? What strategies can I use?
- 4) What do I want to try and do more of to respond to negative treatment from others?

- You will have an opportunity to view all the materials in advance via our website.
- The STORM programme draws on psychological theories and evidence.

What would involvement look like for group members?

- The group facilitator will introduce the programme to group members and see who is interested in taking part. Everyone in the group will already know one-another and will be able to meet at a familiar place.
- A researcher will meet with the interested group members, go through an information sheet and complete consent forms.
- In total, the programme will take up 7 sessions. This includes:
 - The 4-session programme
 - 1 booster session, which includes completing a questionnaire
 - Completing questionnaires as a group on 2 separate occasions: before the programme and 3 months after the programme

Providing support to group members

- We think it is important to hear directly from people about their real-life experiences, which is why we include videos and invite people to share their experiences in the programme. However, these experiences have sometimes involved upsetting events and unfair treatment by others.
- It is possible that the discussions in this programme bring up sad or difficult feelings in participants. For example, watching a video of someone with a learning disability talking about their experience of bullying might make some participants feel sad that this has happened or feel sad because they can relate to this experience. Some participants might also be shocked by the way other people can treat people with learning disabilities.
- We will try our best to support group members who feel this way. Our research aims to boost people's ability and confidence in resisting the negative impact of learning disability stigma.
- It is possible that group members may wish to speak to their carers or friends about their feelings, thoughts and experiences related to the topics discussed as part of the programme, which is why we are giving you this information sheet.

If you feel that you would like support as a carer/supporter of someone with a learning disability, please see the resources below:

Mencap – FamilyHub: An online community for parents and family carers to connect with others, to share triumphs and challenges, and a place for support and tips

<https://www.mencap.org.uk/familyhub>

National Family Carer Network: a charity that aims to promote the voice and rights of family carers supporting a person with a learning disability

<http://www.familycarers.org.uk/>

info@familycarers.org.uk

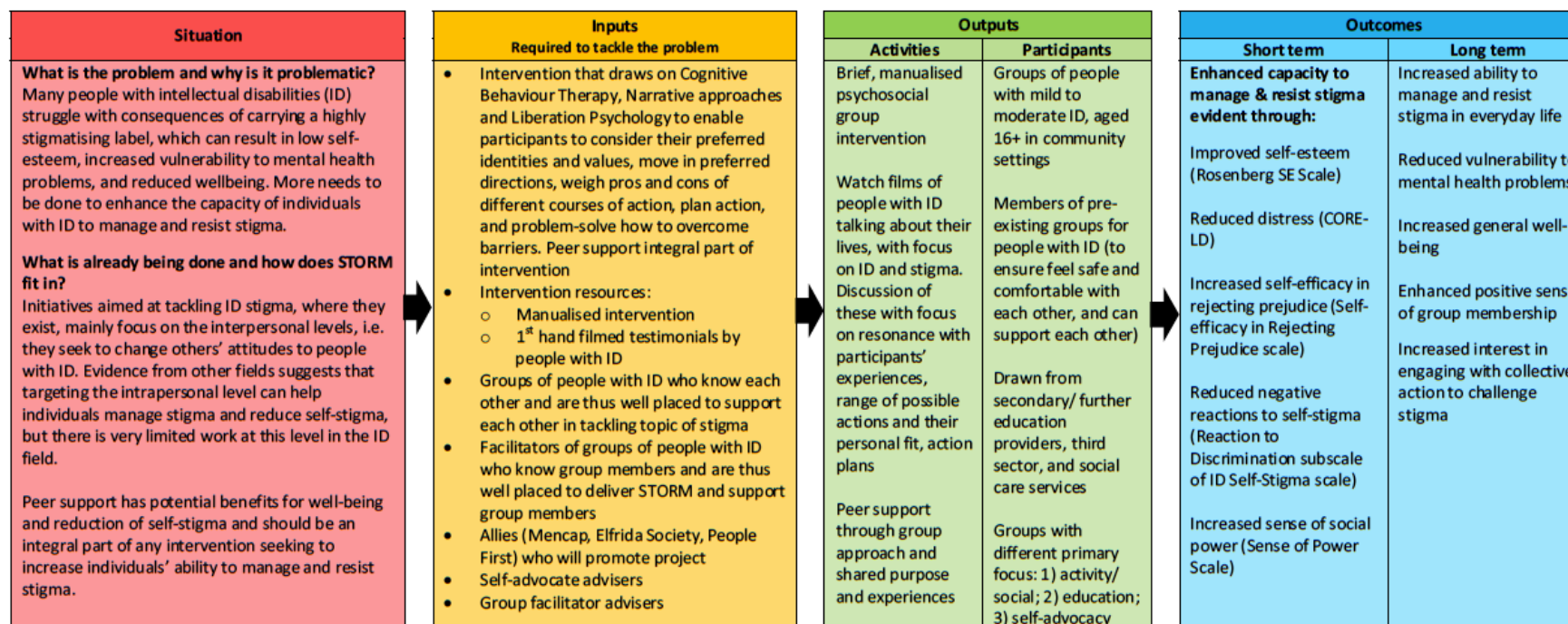
Our contact details can be found on the front page of this document.

We are grateful to Baily Thomas Charitable Fund for their support of this project.

Appendix D:

Logic Model of the Standing Up for Myself (STORM) programme

(Scior et al., personal communication)



Assumptions
<p>Individuals with ID are generally aware that they have an ID (confirmed by Systematic Review, Logeswaran, Richardson & Scior, under review).</p> <p>Awareness of negative connotations of ID label has negative effects on significant proportion of people with ID (confirmed by Scior & Wemer, 2016 and Logeswaran et al., under review).</p> <p>For many, capacity to manage and resist stigma is low by virtue of reduced cognitive and adaptive skills and disempowering environments.</p> <p>Stigma resistance is associated with positive outcomes (confirmed by meta-analysis by Firmin et al., 2017).</p> <p>Stigma management and resistance can be enhanced using psychosocial approaches in this population.</p> <p>The same intervention will be suitable and effective for different subsections of people with mild to moderate ID aged 16+ and different settings.</p>

External factors
<p>Training and ongoing supervision for STORM group facilitators, alongside peer support via user friendly Slack web forum</p> <p>Adherence to manual</p> <p>Ready access to film based materials and equipment</p> <p>Contextual variables (group type and community setting)</p> <p>Powerful external barriers reinforcing stigma and resisting development of new skills/identity</p> <p>Availability of opportunities to try out enhanced skills</p>

Appendix E

A subset of guidance for facilitators provided in the manual

Facilitators' notes and tips

- We recommend that 1.5 hours are ideally set aside for each session.
- We have included optional checklists for each session in the Appendix (pages 55-60) that may be used by facilitators to ensure they have prepared all the necessary materials for the session.
- It is important to ensure all activities are completed as each session is designed as a whole and ends on demonstrating the key message of the session. Therefore, it is particularly important to cover the end activities of the session. We have included printable handouts/posters outlining the key messages for each session (pages 65-69). These may be used as you wish (e.g. displayed in the middle of the room or table, or put up on a wall during the session).
- Use the recommended time limits for each activity as a guide to make sure the group can complete all the activities in each session. Sometimes a less-than sign '<' is used (e.g. <5MIN) to indicate that we would like you to spend less time on this activity if possible.
- If you follow the timings suggested and use a 'parking sheet' (a blank piece of paper or on a whiteboard for example) for any off topic conversations then it should be possible to complete all of the activities (please consider timings when adapting any of the activities for your group). However, should you find that you are running over, you will need to make a quick on the spot assessment of how much you are running over, what activities you have completed and what remains to work through. Here are some helpful hints, tips and things to remember:
 - ▶ To ensure groups run to time it will be important to start on time, even if some people are running late, it is suggested that groups wait no longer than five minutes for late comers. It may be worth discussing with people while waiting if they will be able to stay on an extra five minutes, so you know whether or not you need to adjust your timings.
 - ▶ You may want to ensure you can see the clock in the room you are using or that you have the time easily accessible on the computer or your phone (if you are

Appendix F

An example session plan

Session 2

How are people with learning disabilities treated?

Aims

- To explore the range of treatment experienced by people with learning disabilities from people without learning disabilities
- To explore participants' own personal experiences of being treated positively or negatively by people without learning disabilities

**Key message: It's not OK for people to treat me badly.
I don't have to put up with it.**

Resources

- We recommend the following videos (links on pages 48-50):

Bullying and hate crime experiences – choose one of these videos:

📺 Video 3: "Living with Learning Difficulties and Autism" by Wiltshire Voices

3b: May be more suitable for a younger audience, or

3c: May be more suitable for a more mature audience, or

📺 Video 4: "Kelly and Sue's story: Learning disability hate crime" by Mencap

Others being patronising:

📺 Video 5: "Things People With Down's Syndrome Are Tired of Hearing" on BBC Three

Being treated respectfully – choose one of these videos:

📺 Video 6: "Tom and Robert's Newspaper Delivery" from Person-Centred Support, or

📺 Video 7: "Heavy Load: UK punk band with learning-disabled members"

Other suggestions of suitable videos can be found on page 53 in case facilitators feel any of those are a better fit for their group.

- STORM programme timetable (from Session 1, optional –page 61 or 62)
- A4 Session 2 key message poster (page 66) – you may wish to photocopy this in A3
- Optional Session 2 worksheet (page 75)

- Confidence rating cards (page 70) – you will need a copy for each participant
- Device to take a picture with (camera or phone) or if you don't have consent for photos, you can use the confidence form to record participants' answers (page 71)
- A4 cards or paper, different coloured pens and a flipchart

A facilitator checklist for Session 2 can be found on page 56-57, if you wish to use it.

Activities

- **Recap the key message from Session 1 (10MINS)**
 - Remind the group that they are here for the STORM programme. Ask participants:

“Who can remind us what we talked about last time?”
 - You may use the STORM timetable from Session 1 to track the sessions.
 - Summarise the first session using any approach you deem to be suitable for your group (some suggestions from us on page 8). The key points are:
 - ▶ We spoke about what having a learning disability means to different people.
 - ▶ We discussed what having a learning disability means to people here.
 - ▶ We talked about how having a learning disability is only one part of who you are.

- **Introduce Session 2's aims (<5MINS)**
 - ▶ We will be looking at how other people treat people with a learning disability.
 - ▶ We will be looking at your experiences of how you have been treated by others, and consider how you felt when they happened.
 - You may wish to put the A4 or A3 key message poster (page 66) in the middle of the room or table as a reminder throughout the session.

- **Video discussion (65MINS)**
 - You may want to share an optional Session 2 worksheet (page 75) with participants so they can either on their own or with someone's support, record anything that they would like to take away from the session. This could be in words or pictures.
 - Invite participants to watch 3-4 videos (depending on time), one at a time, showing the range of treatment experienced by people with learning disabilities, both negative and positive. Ask participants to focus on how people with learning disabilities have been treated by other people in each video. We recommend the following videos:

- ▶ Choose between playing Video 3b, 3c and 4 (videos about bullying experiences)
- ▶ Play Video 5 (short video of a person with Down Syndrome talking about other people being patronising) – if you choose to play this video, we would advise that you explain to participants beforehand that some people with Down Syndrome have a learning disability and might have different support needs
- ▶ Play Video 6 or 7, or both (video where people are treated well by others)
- ▶ More video suggestions can be found in the Appendix, if any of the above are deemed inappropriate.

- Prompt discussion after each video:

“How were/was the people/person with learning disabilities in the videos treated?”

“What did you think about that?”

- If participants talk about their own experiences while answering these questions and you are making notes (optional) on a whiteboard or flipchart, you may wish to split the whiteboard or flipchart into “what people in the video said” and “what we said”.

- Once the videos have been watched, invite participants to share their own personal experiences. Ask participants:

“Have you experienced anything similar to the people in the videos we have just watched?”

“Let’s talk about our own experiences and how we have been treated by others who don’t have a learning disability. Firstly, what negative experiences have you had?”

“What positive experiences have you had?”

- Summarise the key points discussed in the session, including the key message: ‘It’s not OK for people to treat me badly. I don’t have to put up with it.’

▪ **Closing question (5MINS)**

- Ask participants:

“At this moment, how confident do you feel about standing up to prejudice?”

- Invite participants to show how confident they feel using the confidence rating cards (page 70)
- Please stress that *“any response is a good response, there’s nothing wrong with not feeling confident”*. This is just so that we can see whether anything changes for people going through the programme.
- Take a picture of all members holding up their answer (with permission) and send this on to your nominated researcher along with your feedback from the session.
- Or, make a note of everyone’s confidence ratings on the chart on page 71, take a picture of this or scan and send it to your nominated researcher along with your feedback from the session.
- Please keep the confidence cards as they will be reused in each session.

Check-out (5MINS)

- See how people are feeling and whether anyone wants to check in with you separately after the session.
- Invite participants to share with friends and family what they have watched and discussed today. Remind them that while it is OK for them to speak about their own experiences to others, it is not OK for them to speak about another group member’s experiences to someone else.
- If requested, share the list of videos with group members so that they can access these themselves (likely with support).
- Thank participants for attending and confirm the date and time of the next session.

Appendix G

Outline of contributions to joint study

Working under the same supervisor, Sophie Colman conducted a research project measuring and conceptualising self-stigma and associated factors in people with intellectual disabilities (Colman, 2018). Her project aimed to develop a tool to measure the extent to which people with learning disabilities internalise stigma, and to get a better understanding of what factors are likely to make individuals with learning disabilities more or less resistant to stigma. Sophie's study also assessed the psychometric properties of the newly developed measure of self-stigma and sense of power. Also contained in the measure were questions regarding self-esteem and psychological distress.

This measure (see Appendix C) was administered to STORM participants. However, for the purposes of my study, only the measures of self-esteem and psychological distress were considered in the write up of the empirical paper. STORM pre-intervention data were jointly collected as they formed part of Sophie's data set. All data analysis, interpretation and project write-ups were completed independently.

Sophie Colman's contributions to STORM feasibility study:

- Collection of pre-intervention data from two STORM groups.
- Consenting of these two groups to the STORM study.

My contributions to Sophie's measurement and conceptualisation of self-stigma study:

- Other collection of STORM pre-intervention data which formed part of Sophie's data set.
- Some support (1/2 day) to collect data from another group of people with intellectual disabilities.

Appendix H

Self-Esteem and CORE-LD questions as included in the study questionnaire

Example

I watch sports on TV	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
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Section 1- About how you see yourself

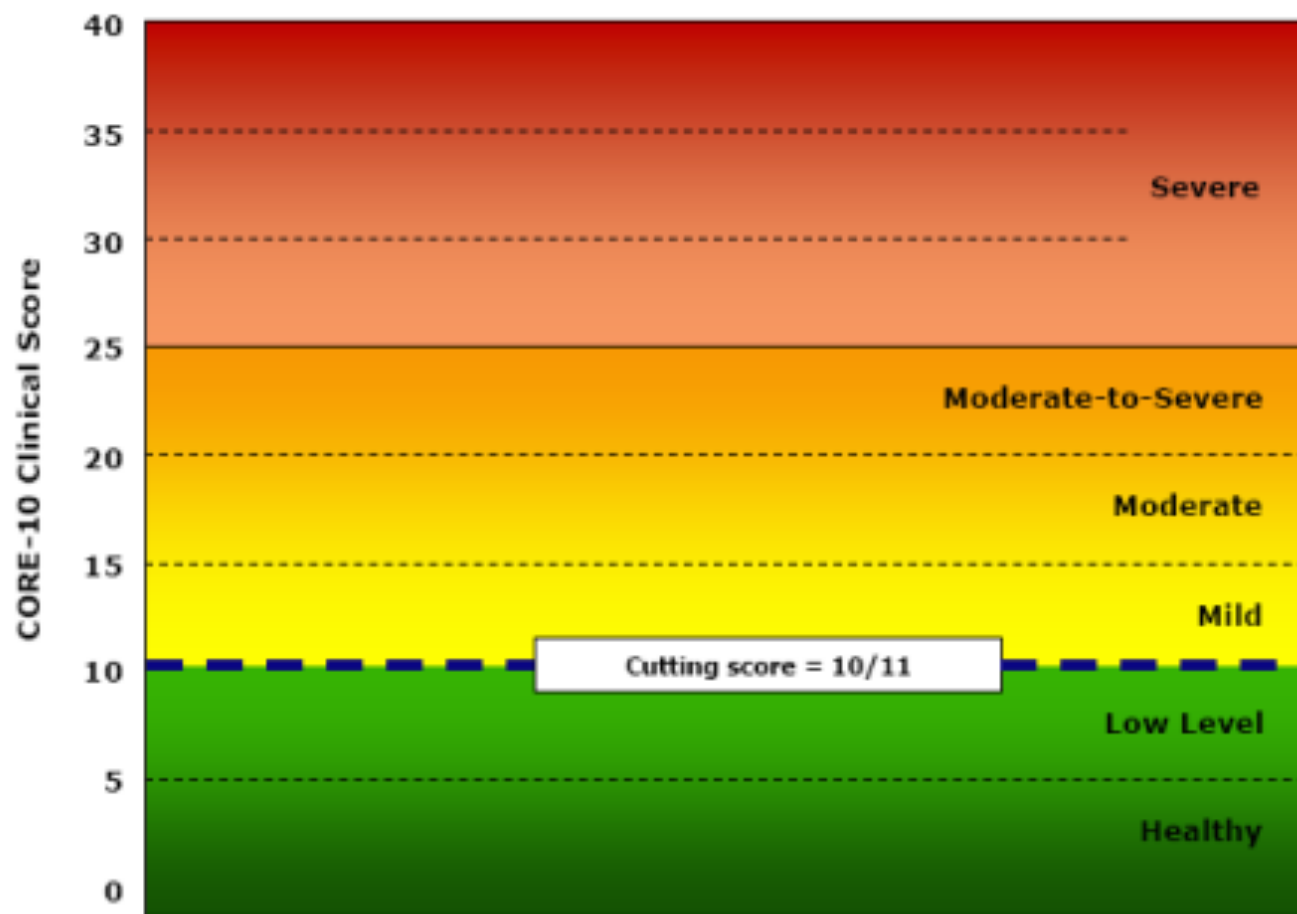
1 I feel that I have a lot of good qualities	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
2 I am able to do things as well as other people	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
3 I like myself	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>

Section 3- Over the last week

12 Have you felt really lonely?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
13 Have you had difficulty getting to sleep or staying asleep?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
14 Have you threatened or shouted at someone?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
15 Have you felt unhappy?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
16 Have you felt people are getting at you?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
17 Have you bottled up angry feelings?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>
18 Have you felt really scared or frightened?	Never <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Always <input type="checkbox"/>

Appendix I

Practice guide for interpreting CORE-10 clinical scores, from CORE website



Appendix J

Group Interview Schedule

Topic	Possible questions
Experience of the programme	<p><i>What did you like about doing the STORM group?</i></p> <p><i>What did you not like about doing the STORM group?</i></p> <p><i>What was the best part of STORM?</i></p> <p><i>What was the worst part of STORM?</i></p>
The programme materials	<p><i>What did you like/not like about the videos?</i></p> <p><i>What did you like/not like about the things you talked about?</i></p> <p><i>What did you like/not like about the things you did together? E.g. make plans, have a celebration event.</i></p>
The outcome measures	<p><i>What did you like about the questionnaires?</i></p> <p><i>What did you not like about the questionnaires?</i></p> <p><i>Were the questionnaires ok to fill out?</i></p>
Positive impact of the intervention	<p><i>Did STORM make anything better?</i></p> <p><i>Did STORM help you do anything new? What did it help you do?</i></p> <p><i>How did STORM help you do that?</i></p>
Adverse impact of the intervention	<p><i>Did STORM make anything worse?</i></p> <p><i>What happened?</i></p> <p><i>How did STORM make that happen?</i></p>

Appendix K

Facilitator Interview Schedule

Topic	Possible questions
Experience of the programme	<p><i>What did you think of the STORM programme? What was it like to deliver the STORM programme?</i></p> <p><i>What was the best/worst part of the programme?</i></p> <p><i>Is there anything that could improve the STORM programme?</i></p>
The programme materials	<p><i>What did you think of the... manual? videos? group discussion topics? group activities?</i></p>
Delivering the intervention (/adherence)	<p><i>How possible was it to follow the manual?</i></p> <p><i>How possible was it to deliver the programme as it is described in the manual?</i></p> <p><i>What helped you to deliver the programme as it is described in the manual?</i></p> <p><i>What got in the way of delivering the programme as it is described in the manual?</i></p>
The outcome measures	<p><i>What did you think of the questionnaires? How possible was it for group members to complete the questionnaires?</i></p>
Positive impact of the intervention	<p><i>Do you think taking part in STORM has had a positive impact on group members? Did they learn anything? Did they make any changes? If so... What positive impact? Was this the case for all group members? What aspect of the group helped that to happen?</i></p>
Adverse impact of the intervention	<p><i>Do you think taking part in STORM has had a negative impact on group members? If so... What negative impact? Was this the case for all group members? What aspect of the group caused that to happen?</i></p>
Future implementation	<p><i>Would you recommend STORM to others inside/outside your organisation? What did you think of the support provided by the research team? Do you think others delivering STORM in the future would be able to with the materials and guidance provided, or do you think they would need opportunities to check in with someone (i.e. one of the researchers)?</i></p>

Appendix L

Qualitative Analysis Indexing Framework

Index annotation: "F" if facilitator said; all other annotations are group member quotes

Acceptability

1. What liked about STORM (F/G)
 - a) Delivering (F)
 - i. Learning new facilitating skills (F)
 - j. Support from research team
 - b) Accessibility
 - c) Videos
 - d) Discussion topics
 - i. Learning about negative experiences of group members (F/G)
 - ii. Learning about strengths/achievements of group members (F)
 - e) Activities
 - i. Doing something different to usual
 - ii. Worksheets
 - iii. Action plans
 - f) Outcome measures
 - g) Group bonding/support
 - h) Other
 - i) Overall message/idea
2. What didn't like about STORM (F/G)
 - a) Delivering (F)
 - b) Accessibility
 - i. Not suitable for people with moderate LD (F)
 - c) Videos
 - d) Discussion topics
 - e) Activities
 - i. Worksheets
 - f) Outcome measures
 - g) Language
 - h) Other
3. What would improve STORM (G/G)
 - a) Changes to manual
 - b) Broaden participants
 - c) Other changes

Feasibility

4. Feasibility of manual (F)
 - a) How easy to follow
 - b) How easy to adhere to manual
5. Feasibility of delivering STORM (F)
 - a) Preparation needed
 - b) Omissions
 - c) Difficulties
 - d) Adaptations/ accessibility
 - i. To questions asked

- e) Importance of knowing group
- f) Size of group
- g) Skills of facilitator
- h) More than one facilitator
- 6. Feasibility of action plans (F/G)
 - a) What helped
 - b) Barriers
- 7. Feasibility of outcome measures (F/G)
 - a) Comprehension/language
 - b) Format
 - c) Response choices
 - d) Support/help needed
- 8. Feasibility of future implementation (F)
 - a) Other organisations
 - b) Use of manual
 - c) Support from research team

Impact

- 9. Positive impact (F/G)
 - a) Memory of programme
 - i. Session themes or content
 - ii. Videos
 - iii. Discussions
 - iv. Activities
 - v. Action plans made
 - b) Stigma resistance
 - i. Acknowledging discrimination/oppression
 - ii. Attitudes/affirmations/resisting labels
 - iii. Meeting/talking with others with an LD
 - iv. Educating others/speaking up
 - v. Successes of action plans
 - vi. Increased confidence/empowering
 - c) Other learning, e.g. about each other;
 - d) Reflection
 - e) Improved relationships
 - f) Increase in motivation
- 10. Negative impact (F/G)
 - a) Upsetting material
- 11. Neutral impact, because group already doing, e.g. speaking up, or not needed

Appendix M

Qualitative analysis - An example of part of an indexed transcript

(Indices in right hand column refer to framework in Appendix F)

Facilitator interview	
What was it like to be part of STORM, running it?	
<i>Eye opening</i>	1diF
<i>Quite empowering for them and for me, because it was a new experience for me. I'd never done anything like that, so it has different challenges and new experiences.</i>	9bviF 1aiF
<i>I quite enjoyed it</i>	1hF
New experiences?	
<i>I already knew two of the participants very well, one of them a little bit, another one was quite new to me. It was quite a journey, even the guys I thought I knew well, I think it goes back to the eye opening bit, it was I got to know them a lot better, saw a different. Thinking of one of the male participants, someone who would come across quite quiet and not bothered about stuff, was actually quite a passionate, independent young man who actually had lots to say and when he was given the opportunity and the forum to do so he did. He started to reflect more on his behaviour and his life at the moment.</i>	1diF1 1diiF 1diiF 9dF

Appendix N

Qualitative analysis – Part of an example chart

Chart 3 What liked – process

Group	Learning new facilitating skills	Contact with research team	Group bonding/support	Other
SA1 (pilot)	<p><i>Facilitator:</i> Felt like a mini-training on using different facilitating skills, including maintaining a similar structure in each session, having a check-in and having a clear message.</p>	<p><i>Group members:</i> Thought staff were polite and nice.</p> <p><i>Facilitator:</i> X</p>	<p><i>Group members:</i> People around the table can help each other and it's nice to discuss things with people with whom you have a good relationship.</p> <p><i>Group member:</i> It's good to talk about problems with people you have a good relationship with.</p> <p><i>Facilitator:</i> Liked that STORM encourages a peer support model. Noted that members listened closely to each other and applauded one another for their successes.</p>	<p><i>Group members:</i> Liked that they learnt different kinds of skills and were encouraged to be honest.</p> <p><i>Facilitator:</i> Liked the structure of having videos and discussions, and the mixture of theory and practical. Liked that STORM allowed the creation of a safe space that was positive even though dealing with a difficult subject. Found it inspiring.</p>
SA2	<p>Group members: X</p> <p>Facilitator: X</p>	<p>Group members: Liked giving feedback and sending work to research team.</p> <p>Facilitator: X</p>	<p><i>Group members:</i> Talking about disability and other things brought the group closer together.</p> <p><i>Facilitator:</i> A group member found it difficult to say positive things about herself, but gained confidence after help from the group.</p>	<p><i>Group members:</i> X</p> <p><i>Facilitator:</i> X</p>

Appendix O

Ethical Approval



21st April 2017

Dr Katrina Scior
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Scior

Notification of Ethical Approval

Re: Ethics Application 0241/003: Development of a psychosocial intervention designed to enhance the capacity of people with intellectual disabilities to manage and resist stigma (CONTEST)

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC for the duration of the project until **1st March 2022**.

Approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form':
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

With best wishes for the research.

Yours sincerely



Dr Lynn Ang
Interim Chair, UCL Research Ethics Committee

Cc: Kristina Fenn & Sophie Colman, Trainee Clinical Psychologists, Research Department of Clinical, Educational and Health Psychology