The long-term outcomes and feasibility of assessing a psychosocial intervention aimed at increasing the capacity of people with intellectual disabilities to manage and resist stigma

Rebecca Cooper

D. Clin.Psy. Thesis (Volume 1)

2019

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: [Signature]

Name: Rebecca Cooper

Date: 2nd October 2019
Acknowledgments

I would firstly like to thank my supervisor, Katrina Scior, for her immense sharing of expertise, knowledge and enthusiasm in all matters research, stigma and intellectual disabilities. I feel incredibly grateful for your supervision throughout this process. Your passion for addressing stigma has been a privilege to witness and the opportunity to do so has shaped me as an individual and professional. I would also like to thank Rob Saunders for his invaluable statistical support, who navigated me through some complicated endeavours with SPSS.

I would like to thank all the participants involved in the study for sharing their time, energy and insights in the shaping and development of the intervention. It was a pleasure to speak with you all.

Lastly, thank you to my family and friends for their continuing love and support, and for reminding me of the light at the end of the thesis tunnel!
Overview

This thesis examines the concept of stigma resistance, exploring both its outcomes as well as its potential for use within interventions for individuals with intellectual disabilities. Stigma resistance has been associated with numerous psychological, behavioural and social benefits. It has also emerged as a promising target for interventions for some highly stigmatised groups of individuals, particularly people with mental health difficulties. However, to date no studies have addressed stigma resistance in individuals with intellectual disabilities.

Part One of the thesis is a conceptual introduction exploring the factors associated with stigma resistance. Research indicates that stigma resistance is associated with a range of psychological, behavioural and social factors. Methodological limitations of the evidence base are noted, with particular attention paid to measurement issues and gaps remaining in the literature.

Part Two presents a mixed methods study investigating the long-term outcomes and feasibility of assessing a psychosocial intervention aimed at increasing the capacity of people with intellectual disabilities to manage and resist stigma. Small increases in self-esteem, sense of power and small decreases in psychological distress and experienced discrimination were found, which did not reach statistical significance due to small sample size. Qualitative findings demonstrated long-term benefits of the intervention for group members, facilitators and significant others. Limitations of the study and directions for further development of the intervention and broader research are considered.
Part Three is a critical appraisal of the research process, examining methodological concerns and wider issues relating to stigma resistance in the intellectual disability field. The appraisal concludes with personal reflections on the process of conducting the research.
Impact Statement

Part one of the thesis has developed our understanding of factors associated with stigma resistance, highlighting the ways in which enhancing stigma resistance may improve the psychological, social and behavioural functioning of individuals. Part two demonstrates the benefit and utility of stigma resistance as a target for intervention for people with intellectual disabilities. Overall, impact produced by this work can be seen across three key domains: research, clinical and societal.

Research Impact

Development and evaluation of the STORM intervention has highlighted the varied potential benefits of targeting stigma resistance at the intrapersonal level in individuals with intellectual disabilities. It is hoped that highlighting these benefits may lead researchers to implement and research intrapersonal level interventions targeting stigma resistance in people with intellectual disabilities, particularly outside of the UK or English-speaking communities, where there remains a gap in culturally appropriate intrapersonal level interventions addressing stigma resistance in people with intellectual disabilities. We also envisage that stigma researchers in other fields might develop adapted versions of the STORM intervention that are suitable for other stigmatised populations.

At a more local level, the research team at UCL, led by Katrina Scior, are continuing research aimed at the further refinement and evaluation of the STORM intervention. Funding has recently been granted for a cluster-randomised feasibility trial of the intervention, through which the proposed methods for economic evaluation will be tested and a process evaluation will be carried out to examine the
delivery of the intervention, stakeholder views on its acceptability, and barriers and facilitators to its future implementation.

In addition to contributing to the field of intellectual disability stigma research, the current study also adds to a body of research that demonstrates and promotes the value of collaboration with service users within the research process. Self-advocates were closely involved throughout the current research and their input was integral to the successful development and evaluation of the STORM intervention. It is hoped that this example may promote the collaboration of researchers and service users in all stages of other studies.

In order to communicate about this study, and maximise possible impact, a STORM project website (https://www.ucl.ac.uk/pals/storm) has been developed to publicise the research and promote it to potential participants. A public engagement event was also held to share research findings with people with intellectual disabilities, researchers, providers from the education, social and third sectors, and the public. There are also plans to publish an article in a peer reviewed journal summarising findings from this study and produce a plain English summary of the research findings for participating organisations and other non-academic users, plus an accessible Easy Read version for participants and other interested individuals with intellectual disabilities.

Clinical Impact

It is hoped that following further effectiveness and economic evaluation, as described above, the STORM intervention should become a public health intervention that could be available to all people with mild to moderate intellectual disabilities.
disabilities in the UK and potentially internationally. This could be delivered across service settings, including educational, social, health and third sector services.

In addition to use of the full STORM intervention, it is also possible that elements of the intervention, perhaps standalone sessions, could be beneficially applied within the clinical field, particularly in therapeutic contexts, where stigma may form part of the formulation of an individual’s presenting difficulties.

**Societal Impact**

It is hoped that through highlighting the factors associated with stigma resistance and the possibility of its use as a target for intervention, this research may encourage public health departments to focus on stigma resistance as a mechanism for change across stigmatised populations and invest funding into the development and implementation of interventions targeting stigma resistance.

The personal accounts of many group members completing the STORM intervention highlight the continuing prevalence of intellectual disability stigma and its detrimental impact. On a macro level it is hoped that the current study also highlights the need for societal attitudes and behaviours towards individuals with intellectual disabilities to change further and be prioritised by policy and law makers.
# Table of Contents

**Part One: Conceptual Introduction** ................................................................. 13

Introduction........................................................................................................ 14

Background......................................................................................................... 15
  Intellectual Disability......................................................................................... 15
  Stigma............................................................................................................... 16
  Stigma and Intellectual Disability ................................................................. 16
  Stigma Management vs Stigma Resistance .................................................... 20
  Stigma Resistance and Intellectual Disability .............................................. 22

Literature Review .............................................................................................. 25
  Method............................................................................................................. 25
  Results............................................................................................................ 27

Conclusions......................................................................................................... 39

Directions for Future Research ......................................................................... 42

References......................................................................................................... 45

**Part Two: Empirical Paper** ............................................................................ 59

Abstract............................................................................................................ 60

Introduction......................................................................................................... 62
  Intellectual Disability and Stigma ................................................................. 62
  Stigma Resistance............................................................................................. 63
  Study Rationale............................................................................................... 66
  Research Questions.......................................................................................... 69

Method............................................................................................................... 70

Participants ........................................................................................................ 70

Measures.......................................................................................................... 73

Design............................................................................................................... 75
Procedure ............................................................................................................. 77
Ethics ..................................................................................................................... 81
Data Analysis ....................................................................................................... 82
Results .................................................................................................................. 85
  Feasibility and Acceptability of Assessing Outcomes at Follow-up .............. 85
  Long-term Impact of the Intervention ............................................................... 92
Discussion ............................................................................................................ 116
  Feasibility and Acceptability of Assessing Outcomes at Follow-up .......... 116
  Impact of Intervention ...................................................................................... 117
  Study Limitations ............................................................................................ 119
  Implications and Further Study ................................................................. 120
References ........................................................................................................... 122

Part Three: Critical Appraisal ............................................................................. 131
Introduction .......................................................................................................... 132
Research Assumptions ......................................................................................... 132
Methodological Issues .......................................................................................... 134
Reflexive Exploration ............................................................................................ 136
Conclusions ........................................................................................................... 140
References ............................................................................................................ 141

Appendices ......................................................................................................... 143
  Appendix A: Multi-level Model of Intellectual Disability Stigma Change
  Interventions ....................................................................................................... 143
  Appendix B: Summary of Research Findings reported by Kristina Fenn .... 144
  Appendix C: Questionnaire Measure ............................................................... 145
  Appendix D: Programme Summary ................................................................. 151
  Appendix E: Participating Groups and Participants .................................... 152
  Appendix F: Information Sheet and Consent Form for Significant Others .... 153
Appendix G: Interview Schedules ................................................................. 156
Appendix H: Ethical Approval Form ............................................................. 162
Appendix I: Information and Consent Forms .............................................. 166
Appendix J: Skewness and Kurtosis Scores .................................................. 184
Appendix K: Subject Group Themes .............................................................. 185
Appendix L: Overall Themes ........................................................................ 188
Part 2: Empirical Paper

Figure 1: Medical Research Council (2008) Functions of Process Evaluation ........ 69
Figure 2: Hypothesised Mechanisms of Change of STORM Intervention ............ 78
Figure 3: Session Attendance Graph ................................................................. 87

Part 3: Critical Appraisal

Figure 1: Hypothesised Mechanisms of Change of STORM Intervention .......... 133

List of Tables

Part 2: Empirical Paper

Table 1: Intervention Recruitment and Retention Effectiveness Operational Criteria ......................................................................................................................................................................................................................................................... 86
Table 2: STORM Intervention Recruitment Targets and Achievements ........... 88
Table 3: Targets and Achieved Timeframes for Follow-up .............................. 91
Table 4: Estimated Marginal Means (Standard Deviations) of Outcome Variables 92
Table 5: Mean Differences of Outcome Variables ........................................... 95
Table 6: Group Member Recollections of the Intervention- Thematic Analysis ..... 98
Table 7: Impact of intervention on group members- Thematic Analysis .......... 101
Part One: Literature Review

Factors Associated with Stigma Resistance: A Conceptual Introduction
Introduction

This project forms the latter stage of a multi-part feasibility and pilot study of a new psychosocial group intervention, aimed at improving the capacity of individuals with intellectual disabilities to manage and resist stigma. Stigmatisation of individuals with intellectual disabilities is widespread (Davies & Jenkins, 1997; Jahoda, Markova & Cattermole, 1988) and is associated with negative consequences for affected individuals in the domains of physical, emotional and social wellbeing (Dagnan & Waring, 2004; Emerson & Baines, 2011; Hatton et al., 2014; Szivos-Bach, 1993; UNESCO, 2015; Verdonschot, deWitte, Reichraft, Buntinx & Curfs, 2009). Interventions are needed to target the different levels at which intellectual disability stigma occurs, including the structural, interpersonal, familial and intrapersonal levels (Scior & Werner, 2016a). Efforts have been made to address intellectual disability stigma at the structural level, for example through the introduction of laws and policies to protect the rights of individuals with disabilities (Equality Act, 2010; United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006), and at the interpersonal level, where education and contact between people with and without intellectual disabilities have been used as means to challenge inaccurate stereotypes towards people with intellectual disabilities (Freudenthal, Boyd & Tivis, 2010; Rae, McKenzie & Murray, 2011; Seewooruttun & Scior, 2014; Werner, 2015). However, there have been no published evaluations of intrapersonal level interventions that explicitly aim to help people with intellectual disabilities manage and resist stigma.

We aimed to address the paucity of intrapersonal level interventions targeting intellectual disability stigma by assessing the feasibility of “STORM” (STanding up
fOR Myself), a new intervention for individuals with intellectual disabilities which promotes their own capacity to manage and resist stigma, with the aim of improving their wellbeing and reducing the risk of self-stigmatisation and associated negative outcomes resulting from exposure to negative attitudes and discrimination. Specifically, as the latter stage of the feasibility and pilot study, the current study used a within subjects repeated measures design to compare the trajectory of time zero (baseline, pre-intervention), time one (intervention completion) and time two (follow-up) levels of self-esteem, psychological distress, experienced discrimination, and sense of social power. Additionally, semi-structured interviews with participants were conducted to assess the acceptability, feasibility and longer-term subjective impact of the STORM intervention on STORM participants. Interviews with STORM participants were triangulated by completion of semi-structured interviews with group facilitators and significant others, including family, friends and paid support staff. The research is intended to inform further development of the STORM intervention and lays the ground for a future randomised controlled trial. This literature review considers the theoretical background motivating this study.

Background

**Intellectual Disability**

Intellectual disability has been defined as (1) deficits in intellectual functioning, indicated by a full-scale IQ below 70; and (2) deficits in adaptive functioning that affect how a person copes with everyday tasks; both of which have their onset during childhood i.e. before 18 years of age (American Psychiatric Association, 2013). The Learning Disability Observatory estimated that in 2015
there were 1.1 million people with intellectual disabilities living in England (Public Health England, 2016).

**Stigma**

Stigma is the process by which certain groups are marginalised and devalued by society, because their values, characteristics or practices differ from a dominant cultural group (Link & Phelan, 2001). Goffman (1963) described stigma as the process by which the reaction of others spoils normal identity. Popular conceptualisations of stigma commonly include components of labelling, stereotyping (attaching negative evaluations to an ascribed label), and prejudice (endorsement of negative stereotypes), which lead to a loss of status and discrimination experienced by the stigmatised individual or group (Rüsch, Angermeyer & Corrigan, 2005). Importantly, stigma occurs within the context of power differentials between those that do the ‘labelling’ and those that are ‘labelled’ (Link & Phelan, 2001).

**Stigma and Intellectual Disability**

The experience of stigma is shared by many individuals with intellectual disabilities. Research has shown that people with intellectual disabilities are aware of the public stigma directed towards their disability, and frequently endorse statements related to personal experiences of stigma and discriminatory behaviour such as “people talk down to me”, “people on the street look at me in a funny way”, and “people treat me like a child” (Ali, Strydom, Hassiotis & King, 2008). Following interviews exploring the treatment of individuals with intellectual disabilities, Jahoda, Markova and Cattermole (1988) concluded that “stigma for
them was not an abstract notion but something with which they had to cope in their everyday lives” (p. 113). A recent review of 16 studies looking at how people with intellectual disabilities view their ascribed label found that the majority are aware of their ascribed label or acknowledge they are “different”, and most recognize that others view the label negatively and express subsequent feelings of shame, anger and powerlessness (Logeswaran, Hollett, Zala, Richardson & Scior, 2019).

The above definition of stigma by Rüscher et al. (2005), which highlights the centrality of stereotypes in stigmatisation, can support an understanding of the process by which individuals with intellectual disabilities become stigmatised. Stereotypes form a central role within the process of stigmatisation, and a range of widely endorsed negative stereotypes about individuals with intellectual disabilities exist. A review of popular media portrayals of people with intellectual disabilities found that they tend to be shown as one-dimensional, vulnerable characters (Special Olympics, 2005). These depictions often elicit a mixture of pity, discomfort and fear among those without intellectual disabilities (Jahoda, Wilson, Stalker & Cairney, 2010; Scheerenberger, 1983).

In addition to the prevalence of negative stereotypes of this population, individuals with intellectual disabilities are also disempowered by a social hierarchy that allows those with more power to determine their access to resources, rights and opportunities. Their relative lack of social, economic and political power allows stigmatisation to occur and continue, since the exercise of power is integral to the process of stigmatisation (Scior & Werner, 2016b).

Stigma researchers tend to regard stigma as a social construction. According to this explanation, cultural beliefs dictate which attributes are stigmatised and the
specific content of stereotypes attached to those attributes. This accounts for the variability in the attributes, behaviors and groups that have been stigmatised across historical, social and cultural contexts (Crocker, Major & Steele, 1998).

Despite this, evolutionary theorists have highlighted the commonality across cultures in some of the attributes which are stigmatised, including disability. They argue that stigma has a functional role in terms of meeting human needs, and that the cognitive adaptations which humans have developed in order to solve problems associated with group living have led them to stigmatise those possessing certain attributes. One theory, which according to Scior (2016b) can help to explain why intellectual disability is stigmatised, is evolutionary theory, which proposes that central to the stigmatisation of individuals with disabilities lies a disease-avoidance process. According to this process avoidance of contact with disabled individuals is driven by misconceptions that disability is infectious. This theory argues that humans have evolved such that in the presence of a stigmatised individual, specific affective (e.g. disgust), cognitive (e.g. disease-related concepts) and behavioral (e.g. avoidance) responses are elicited. Another evolutionary theory underpinning stigmatisation is that possessing a disability curtails an individual from contributing equally to society, which reduces the overall functioning and resources of a society and poses potential risk to a group (Neuberg, Smith & Asher, 2000). Evolutionary theories also account for differing changes in levels of stigmatisation of those with physical and intellectual disabilities over time. Physical disability has experienced a relatively greater reduction in stigma in recent decades than intellectual disability, as the value of cognitive skills has grown in importance (Green, 2009; Scior, 2016b).
Furthermore, social psychologists have also highlighted that stigmatisation may occur as a way to meet broader socio-psychological goals, namely to enhance the self-esteem and social identity of more powerful individuals, or to justify a particular social, economic, or political structure (Crocker et al., 1998). Lerner (1965) proposed the Belief in a Just World concept, which states that people have a need to believe that their environment is a just and orderly place where people get what they deserve. Goffman (1963) applied this concept to support understanding of the poor treatment of vulnerable individuals, proposing that more powerful individuals devalue vulnerable individuals, blaming them in some form for their vulnerability, in order to protect themselves from a sense of vulnerability and justify their relative advantage within society.

Intellectual disability stigma is displayed in both explicit forms, for example through verbal insults (Jahoda et al., 1988) and bullying (Mencap, 2000), as well as more subtle forms which lead to reduced quality of life for individuals with intellectual disabilities. Ditchman, Kosyluk, Lee and Jones (2016) detail that the stigmatisation of individuals with intellectual disabilities can result in their exclusion from education or segregated education (UNESCO, 2015), denial of work opportunities (Hatton et al., 2014), fewer social relationships and reduced levels of community participation (Verdonschot et al., 2009), poorer medical care and physical health outcomes (Emerson & Baines, 2011) and reduced choice and autonomy in decision making (Davidson et al., 2015). A body of evidence demonstrates that stigmatisation can also negatively affect the psychological well-being, self-esteem and mood of individuals with intellectual disabilities (Dagnan & Waring, 2004; Szivos-Bach, 1993). Importantly, it has been suggested that people with intellectual disabilities may be more likely to experience distress resulting from
stigma than those without intellectual disabilities. This is due to high levels of other social adversities experienced by this population, and their reduced access to coping strategies and problem-solving skills (Ali, King, Strydom & Hassiotis, 2015). The damaging effects of stigma have broader implications for wider society through the increased long-term health and social care costs associated with them (Hatzenbuehler, 2009; Hatzenbuehler, Phelan & Link, 2013).

**Stigma Management vs Stigma Resistance**

As a prevalent and damaging process, understanding how stigma may be addressed by affected individuals is crucial. Two key processes, stigma management and stigma resistance, have been highlighted. As described by Emlet (2004), stigma management involves a stigmatised individual making protective efforts to enable themselves to cope with the negative experience of being stigmatised and its effects, such as managing the pain and loss of opportunities resulting from stigma. Emlet (2004) compared stigma management to “putting up walls to protect oneself from assault” (p.594). Stigma management can be considered a passive act by this definition.

Stigma resistance goes beyond avoiding the impact of stigma to the use of more active attempts to create positive outcomes. It falls within an empowerment model of developing resilience, which views individuals as active participants able to create positive outcomes for themselves and others, rather than passive targets that focus only on avoiding negative outcomes (Oyserman & Swim, 2001). Emlet (2004) has likened this more active approach to stigma as “lobbing cannonballs over the walls if necessary” (p.594).
Stigma resistance is hypothesised to involve several processes. Stigma deflection (Thoits, 2011) is considered to be central to the stigma resistance process and involves recognising how one is dissimilar from a stereotype and resisting it through demonstrating that the stereotype either does not apply or only partly applies to oneself. This protects against the internalisation of stigma (self-stigma) and the risk of negative attitudes being directed towards the self (Griffiths, Mond, Murray, Thornton, & Touyz, 2015; Ritsher & Phelan, 2004). Deflection has also been considered to imply changing something about the self in order to ‘camouflage’ one’s difference (Goffman, 1963; Thoits, 2011). Manago, Davis and Goar (2017) suggest that in this way stigma deflection maintains interactional ‘smoothness’ by minimising the negative consequences of stigmatisation but not directly addressing the stigmatising social structure. Within the mental health literature stigma deflection has been highlighted as a key intrapersonal component of stigma resistance (Firmin et al., 2017a; Ritsher & Phelan, 2004). Another process central to stigma resistance is stigma challenging, which entails either direct confrontation of the prejudiced actions of others or education and training of those who stigmatise. Stigma challenging demands change at interpersonal and structural levels, and in this way can be said to be aligned with social activism and advocacy (Buseh & Stevens, 2006; Firmin et al., 2017a; Thoits, 2011). Sustained verbal assertion of one’s rights and needs against those who stigmatise can be empowering and increase confidence, self-esteem and sense of power in marginalised groups (Nabors et al., 2014; Puhl & Brownell, 2003). It is likely that people utilise methods of stigma deflection and stigma challenging interchangeably, according to their context (Thoits, 2011).

Bringing these theoretical explanations into a framework to understand stigma resistance, Firmin et al. (2017a) proposed a conceptual model of stigma
resistance from the perspective of peer support workers in recovery from serious mental health problems. In this model, resisting stigma can occur at three levels; (1) the personal level, which involves not believing stigma, noticing stigmatising thoughts, educating oneself about diagnosis, and maintaining recovery and developing a meaningful identity and purpose outside of diagnosis; (2) the peer level, which may involve using one’s experience to help others, peer-driven service involvement, and informal assistance to friends and family with difficulties; and (3) the public level, which may involve public disclosure of diagnosis, educating others, advocating for others and questioning stigma more broadly. This model provides a useful framework to guide the development and evaluation of interventions targeting stigma and the capacity of individuals to resist it.

**Stigma Resistance and Intellectual Disability**

Whilst research on stigma resistance within the field of intellectual disability is in its infancy, an understanding of the processes involved in stigma resistance points to the hypothesis that it is likely to be harder to enact by members of this population. Weaker cognitive abilities within the population are likely to interfere with the capacity to deflect stigma, which requires an individual to have an awareness of stereotype content and assess its applicability to oneself. Additionally, poorer communication skills common among people with intellectual disabilities are likely to interfere with their ability to directly challenge those holding stigmatising beliefs. Nonetheless, enhancing the ability of individuals with intellectual disabilities to resist stigma is hypothesised to have a large potential impact due to the high levels of stigma faced by this population and is indicated due to promising findings from other populations. There is growing evidence indicating that stigma resistance
may be associated with recovery outcomes, independent of the level of self-stigma experienced by an individual, across various stigmatised populations, including those with diagnoses of schizophrenia (Campellone, Caponigro & Kring, 2014; Sibitz et al, 2011), eating disorders (Griffiths et al., 2015), irritable bowel syndrome (Taft, Ballou & Keefer, 2012), obesity (Puhl & Brownell, 2003), and women with HIV (Buseh & Stevens, 2006).

Scior and Werner (2016a) developed a structural model to reflect the different levels which interventions targeting intellectual disability stigma should focus upon, including structural, interpersonal, familial and intrapersonal levels. Efforts to address intellectual disability stigma thus far have been largely concentrated at the structural and interpersonal levels. Structural level interventions focus on social forces and institutions through affecting media, legislation and governmental or organisational policy. These methods have potential to affect society at a broad level. Examples of intellectual disability stigma interventions at this level include the introduction of laws and policies aimed at protecting the rights of individuals with intellectual disabilities to the same access to services and quality of care as those without disability and preventing discrimination against people with intellectual disabilities at both national and international levels (Equality Act, 2010; United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006). Due to the challenges inherent in trying to evaluate the impact of legislative and policy change there is no evidence currently on the specific impact of these structural level interventions on intellectual disability stigma. Interpersonal level interventions focus on the interactions between stigmatised and non-stigmatised individuals. Within the field of intellectual disability such interventions involve education and interpersonal contact between individuals with and without
intellectual disability as routes to challenging inaccurate stereotypes. Research has demonstrated that interpersonal interventions focussed on education alone increase knowledge about intellectual disability (Campbell, Gilmore & Cuskelly, 2003; MacDonald & MacIntyre, 1999; Seewooruttun & Scior, 2014), however, research in the field of mental health has found that the impact of education-based approaches on stigma change is small and often not sustained (Corrigan, Morris, Michaels, Rafacz & Rüsch, 2012). Interventions involving direct contact with stigmatised groups have been found to be more effective in achieving long-lasting attitudinal and behavioural change in both the mental health (Corrigan et al., 2012) and intellectual disability field (Freudenthal, Boyd & Tivis, 2010; Seewooruttun & Scior, 2014).

Interventions at the structural and interpersonal levels highlight a growing awareness of intellectual disability stigma and commitment to address it. Despite this, familial and intrapersonal level interventions targeting intellectual disability stigma are lacking (Scior & Werner, 2016a).

At the intrapersonal level, some psychosocial interventions have been developed to enable individuals with intellectual disabilities to cope with their stigmatised identity, thereby falling within the category of stigma management interventions. Szivos and Griffiths (1990) developed Consciousness Raising Groups with the aim of supporting people with intellectual disabilities to accept their underlying impairment, learn to cope with their stigmatised identity, and develop a positive group identity. Narrative therapy, when used within intellectual disability services, can also act as an intrapersonal approach to resisting stigma, through the deconstruction of dominant and stigmatising stories and consideration of the power differentials underpinning them (Scior & Lynggaard, 2006). These interventions target self-stigma, which refers to the process by which people in a discriminated
group internalise stereotypes held by others into their own sense of self and identity, thus increasing their sense of being different or inferior (Corrigan & Watson, 2002). Self-stigma is associated with various negative outcomes in people with intellectual disabilities, including negative self-evaluations, negative social comparisons, symptoms of depression and anxiety (Ali et al., 2012) and decreased self-esteem (Jahoda et al., 2010). Despite the promise of these interventions, further research is required to assess their impact on self-stigma. Efforts to resist stigma at the intrapersonal level have been developed for some highly stigmatised groups of individuals, for example people with serious mental health difficulties (Fung, Tsang & Cheung, 2011; Luckstead et al., 2011). However, there have been no published evaluations of intrapersonal level interventions that explicitly aim to help people with intellectual disabilities to resist stigma.

**Literature Review**

In order to justify stigma resistance as a target for intervention within the intellectual disability population, it is important that the outcomes associated with the concept are well understood. This will develop our knowledge of the potential impact that stigma resistance interventions may have and will guide us in assessing whether measures of stigma resistance used to assess stigma resistance interventions for people with intellectual disabilities measure appropriate constructs or require further development. A review of the relevant literature is therefore indicated.

**Method**

**Search Strategy.** To evaluate literature on outcomes associated with stigma resistance, the electronic databases SCOPUS, Web of Science and ProQuest were
searched (November 5, 2018) using the following search terms: ‘stigma resistance’ AND ‘outcomes’. Three databases were included in the search as research on stigma resistance is in its infancy, and it was therefore important to ensure that as large a body of relevant research on this topic was captured as possible. The references of all included studies were searched to identify any further relevant studies.

**Review Process.** Across the three databases 220 results were returned. To refine the search, any papers not written in English were excluded from the review. Due to the limited number of studies within the field, no studies were excluded based on the date of publication.

Once papers which were duplicated or irrelevant to the review topic were omitted, 15 relevant studies remained. Of these, 14 identified associations between stigma resistance and a range of psychosocial, psychiatric and behavioural factors in individuals with different stigmatised conditions. Seven studies researched individuals with psychosis (Firmin, Luther, Salyers, Buck & Lysaker, 2017b; Nabors, Yanos, Roe, Hasson-Ohayon, Leonhardt, Buck & Lysaker, 2014; O’Connor, Yonos & Firmin, 2018; Olçun & Altun, 2017; Park, Bennett, Couture & Blanchard, 2013; Raij, Korkeila, Joutsenniemi, Saarni & Riekki, 2014; Walston, 2011), four researched individuals with a range of mental health conditions (Chan, Lee & Mak, 2018; Firmin, Luther, Lysaker, Minor & Salyers, 2016; Lau, Picco, Pang, Jeyagurunathan, Satghare, Chong & Subramaniam, 2017; Lien, Kao, Liu, Chang, Tzeng, Lu & Loh, 2015), one researched individuals with depression and bipolar disorder (Brohan, Gauci, Sartorius & Thornicroft, 2011), one researched individuals with eating disorders (Griffiths, Mond, Murray, Thornton & Touyz, 2015), and one researched individuals with irritable bowel syndrome (Taft, Ballou & Keefer, 2013).
The final study was a confirmatory factor analysis of a new scale of stigma resistance (Firmin, Lysaker, McGrew, Minor, Luther & Salyers, 2017c).

Review of the literature cited in these publications identified another two relevant studies. These identified associations between stigma resistance and a range of psychosocial, psychiatric and behavioural factors in individuals with psychosis (Bifftu, Dachew & Tiruneh, 2014; Sibitz, Unger, Woppman, Zidek & Amering, 2009).

Results

In total 17 articles, as highlighted above, were included in the review. Studies reported in these articles used the Internalised Stigma of Mental Illness scale (ISMI) (Ritsher et al., 2003) to measure stigma resistance. The ISMI is a measure of the subjective experience of stigma and has been used frequently within research looking at factors associated with stigma resistance. It assesses five domains: alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. One study included in the review did not rely on use of the ISMI, and instead measured stigma resistance through use of functional MRI, to understand the neuropsychological basis of stigma resistance (Raij, Korkeila, Joutsenniemi, Saarni & Riekki, 2014).

Psychological Factors

There is growing evidence across various stigmatised populations indicating that stigma resistance may be associated with a range of psychological factors, independent of the level of self-stigma experienced by an individual.
**Internalised Stigma.** Correlational research by O’Connor et al. (2018) using the ISMI found that stigma resistance was negatively associated with self-stigma in individuals with schizophrenia and schizoaffective disorder. This finding has been replicated in correlational research with individuals with depression and bipolar disorder (Brohan et al., 2011) and mental health problems (Firmin et al., 2016b; Lau et al., 2017; Lien et al., 2015). Firmin et al. (2016b) highlighted that the magnitude of the relationship between stigma resistance and self-stigma was not so large as to suggest that self-stigma and stigma resistance are two sides of the same construct. Although strongly related, several associations found in their meta-analysis supported the position that stigma resistance is distinct from self-stigma, for instance, stigma resistance was significantly related to negative symptoms of psychosis, a relationship not observed in relation to self-stigma.

Both Thoits (2011) and Firmin et al. (2017a) suggest that challenging stigma and developing a positive, meaningful identity separate from one's mental health problems are essential to the process of stigma resistance. When restricting analyses to only those with moderate to high levels of self-stigma, O’Connor et al. (2018) found that greater stigma resistance was associated with lower stereotype endorsement, but not other aspects of self-stigma assessed by the ISMI (alienation, discrimination experience, social withdrawal). This suggests that in individuals with moderate to high levels of self-stigma, stigma resistance is most closely associated with the ability to challenge stereotypes. Similarly, research suggests that lower agreement with negative stereotypes may be predictive of greater stigma resistance in individuals with severe mental health problems, whilst other components of self-stigma are not (Lau et al., 2017; Lien et al., 2015; Nabors et al., 2014).
Whilst self-stigma has been conceptualised by some researchers as an outcome of stigma resistance (Ritsher et al., 2003; Thoits 2011), others propose the reverse relationship (Lau et al., 2017; Sibitz et al., 2011). The cross-sectional design of research in this area to date does not allow us to establish the direction of the association between stigma resistance and self-stigma. Investigation using longitudinally designed research is required to address this gap.

Meta-cognition. Meta-cognition is the ability to think about one’s own thinking, the thinking of others, to recognise that one is not the centre of the world, and to use that knowledge to solve problems. Correlational studies of self-stigma (which have used the ISMI) and meta-cognition have shown that greater levels of stigma resistance are related to greater capacity for meta-cognition in individuals with psychosis (Firmin et al., 2017b; Nabors et al, 2014). Whilst the correlational nature of this research prevents us understanding the direction of the association, the association implies that stigma resistance may involve the reforming of ideas about oneself and others when stigmatised, rather than merely avoiding internalised stigma.

Emotion Regulation. Neuropsychological research with individuals with psychosis has used functional magnetic resonance imaging to establish brain regions implicated in experimental tasks of resisting stigma (Raij, Korkeila, Joutsenniemi, Saarni & Riekki, 2014). Findings have suggested that the medial prefrontal cortex (a region implicated in emotion regulation) is used during the process of resisting the stigma of schizophrenia. As highlighted by the authors, the medial prefrontal cortex is related to multiple neuronal networks and cognitive functions, therefore any inference about emotion regulation in stigma resistance based solely on medial
prefrontal cortex activation would be an oversimplification. However, research has consistently demonstrated the strong connection between the medial prefrontal cortex and the amygdala (which is also used in emotion regulation tasks), implicating at least its partial involvement in the emotion regulation function. The research concluded that these findings suggest that individual stigma resistance may be associated with the process of emotion regulation. Whilst further research on this topic is required, should emotion regulation be found to be important for stigma resistance this would highlight that interventions targeting stigma resistance should include components of emotion regulation skills, such as monitoring, evaluating and modulating emotions.

**Illness Acceptance.** Correlational studies have also established an association between stigma resistance (measured with the ISMI) and illness acceptance in individuals with schizophrenia (Walston, 2012). Their findings indicate that illness acceptance may either predict stigma resistance or be an outcome of it. In this study illness acceptance was measured using the Positive Aspects of Mental Illness Subscale of the Stigma Scale (King, Dinos, Shaw, Watson, Stevens & Passetti, 2007). The study found that illness acceptance was a significant predictor of mental health recovery. Walston (2012) concluded that self-stigma can be viewed as a dynamic variable where components of alienation, discrimination, stereotype endorsement and social withdrawal on the one hand interact with stigma resistance on the other to produce an overall effect which can predict whether a person with schizophrenia can accept the illness and move forward in mental health recovery or not. Accordingly, stigma resistance appears to play a crucial role in facilitating the process of illness acceptance and recovery.
Empowerment. In their correlational research of people with schizophrenia and schizoaffective disorder, Sibitz et al. (2009) found that stigma resistance correlated positively with levels of empowerment. Participants completed the ISMI to assess individual levels of stigma resistance, alongside measures of various psychiatric and psychosocial factors. Empowerment was measured using the Rogers Empowerment Scale (Rogers, Chamberlin, Ellison & Crean, 1997) which assesses an individual’s overall sense of empowerment, alongside five dimensions, including (1) self-efficacy and self-esteem, (2) power and powerlessness, (3) community activism, (4) optimism and control over the future, and (5) righteous anger. Greater stigma resistance was associated with greater levels of overall empowerment and higher scores on all five dimensions of empowerment (Sibitz et al., 2009).

Coping Style. Research has also suggested a relationship between stigma resistance and coping style. O’Connor et al. (2018) found that in relation to coping with symptoms of schizophrenia and schizoaffective disorder, stigma resistance was positively correlated with problem-centred coping (a way of targeting the causes of stress in practical ways), while self-stigma was positively correlated with avoidant coping. These findings provide additional support for the proposition that stigma resistance is an active process that may be affected by adaptive coping strategies (Firmin et al., 2017a). Depending on the direction of this relationship, interventions that improve an individual’s confidence in their ability to cope with the stress of stigma may also help empower them to resist stigma, if coping style is indeed a predictor of stigma resistance. Alternatively, increasing stigma resistance may lead to the development of greater problem-centred coping. It is plausible that both of these may be valid pathways, posing questions for future research.
Psychiatric Symptoms. Research by Nabors et al. (2014), involving self-completion of the ISMI and informant ratings of measures of positive and negative symptoms of psychosis, found significant negative correlations between stigma resistance and negative symptoms in individuals with schizophrenia and schizoaffective disorder. This indicates that greater stigma resistance appears related to lower levels of negative symptoms, such as reduced emotional range, poverty of speech and lack of interest and drive.

Research has also shown stigma resistance to be negatively correlated with symptoms of depression (Sibitz et al., 2009), and therefore may act as a protective factor for depression or a target for intervention for those already experiencing depression, to support the move towards recovery. Correlational studies investigating relationships between similar variables of stigma resistance and psychiatric/psychosocial factors have replicated this negative correlation between stigma resistance and depressive symptoms in other populations, including mental health outpatients with a range of diagnoses, including major depression, bipolar disorder, social phobia, panic disorder and obsessive compulsive disorders in Taiwan (Lien et al., 2015) and Singapore (Lau et al., 2017), and individuals recovered from eating disorders (Griffiths et al., 2015).

Insight. In addition to the beneficial outcomes of stigma resistance on depression suggested by research, studies have also demonstrated that stigma resistance is associated with a range of functioning related outcome variables. One of these is insight, which can be defined as possessing awareness of an illness and its attribution and treatment (Reddy, 2016). In a meta-analysis by Firmin et al. (2016b) of 48 studies with adults with mental health problems, greater stigma resistance was
associated with greater levels of insight. This suggests that an outcome of stigma resistance may be increased insight, although due to the correlational nature of the research it is also possible that insight may precede improvements in stigma resistance.

**Hope.** Research has also demonstrated that stigma resistance is positively associated with hope. Similar to the cross-sectional questionnaire studies referred to above, Olcun and Altun (2017) completed a correlational study looking at relationships between stigma resistance, self-stigma and levels of hope in individuals diagnosed with schizophrenia in Turkey. A positive correlation was found between the mean score on the stigma resistance subscale of the ISMI and the total mean score on the Herth Hope Scale (Herth, 1991). As respondents’ levels of stigma resistance increased, their levels of hope also increased. In support of this finding, the meta-analysis by Firmin et al. (2016b) also found greater levels of stigma resistance to be associated with greater levels of hope in individuals with a range of mental health problems. Furthermore, research by Lien et al. (2015) found that greater levels of stigma resistance were associated with lower levels of hopelessness, as measured with the Beck Hopelessness Scale (Beck, Weissman, Lester & Trexler, 1974), among individuals with a range of mental health problems. Again, due to the cross-sectional design of this research the direction of this relationship is unclear. However, it indicates that attempts to increase stigma resistance may also lead to greater levels of hope, and that instilling hope may be an effective target for interventions aimed at increasing resistance to stigmatisation.

**Self-esteem & Self-efficacy.** Other key psychological factors found to be associated with stigma resistance are self-esteem (the overall subjective emotional
evaluation of one’s own worth (Hewitt, 2009)), and self-efficacy (the overall belief in one’s ability to succeed in specific situations or tasks (Bandura, 1977)). Experiences of stigmatisation and discrimination have been found to be associated with lower self-esteem (Hayward, Wong, Bright & Lam, 2002) and self-efficacy (Kleim et al., 2008; Vauth, Kleim, Wirtz & Corrigan, 2007) in individuals with mental health diagnoses. However, as noted by Thoits (2011), these correlations are modest. Research indicates that although a majority of mental health service users experience self-derogation as a result of perceived or experienced stigma, smaller groups instead respond with righteous anger or remain indifferent to the experience of stigma. Stigma resistance can be viewed as a protective mechanism by which stigmatised individuals can reduce and counter the negative impact of stigmatisation on their levels of self-esteem and self-efficacy (Thoits, 2011). Indeed, substantial research supports the positive association between stigma resistance and self-esteem across populations, including those with psychosis (O’Connor et al., 2018; Sibitz et al., 2011), mental illness (Lau et al., 2017; Lien et al., 2015), and irritable bowel disease (Taft et al., 2012). Research also supports the positive association between stigma resistance and self-efficacy, in those with mental illness (Lien et al., 2015) and irritable bowel disease (Taft et al., 2012).

**Quality of Life and Life Satisfaction.** Another functioning related variable that has been implicated in literature on stigma resistance is quality of life. Quality of life is commonly measured across the domains of physical health, psychological health, social relationships and the environment, and is routinely assessed from an individual’s perspective on their own life. A commonly used measure of quality of life is the WHOQOL-BREF (WHOQOL Group, 1998). Firmin et al. (2016), in their meta-analysis of a mental health population, found large, significant effect sizes for
the relationship between stigma resistance and quality of life \( (r = 0.51, p < 0.001, k = 17) \), suggesting that this domain may be particularly relevant to stigma resistance.

Findings of a positive relationship between stigma resistance and quality of life have been replicated in correlational studies of a mental health population in Singapore (Lau et al., 2017) and across different populations, including individuals with psychotic disorders (Sibitz et al., 2009) and those with physical illness. Specifically, research with individuals with irritable bowel disease (Taft et al., 2012) found a significant positive correlation between stigma resistance and health-related quality of life. In this study, health-related quality of life was assessed using the Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al., 1989) which evaluates an individual’s bowel and systemic symptoms, as well as social and emotional functioning. Further research is required to understand whether stigma resistance precedes improvement in quality of life, or whether improved quality of life is a prerequisite for effectively resisting stigma, or indeed if the relationship between stigma resistance and quality of life is bidirectional.

Additionally, research by Chan et al. (2018), who administered cross-sectional questionnaires, used structural equation modelling to demonstrate that stigma resistance was positively associated with life satisfaction in individuals with mental illness. Importantly this association was mediated by self-stigma content and process. This highlighted the potential that increasing stigma resistance may hold in alleviating self-stigmatising thoughts, which are likely to adversely affect life satisfaction (Sibitz et al., 2011). Interestingly the study also found that mindfulness was positively associated with stigma resistance, and this association was mediated by self-compassion and psychological flexibility. The authors therefore concluded that mindfulness may increase the capacity for stigma resistance by enhancing self-
compassionate attitudes and the ability to deal with societal stigma non-judgementally, thereby reducing the impact of self-stigma content and process.

Overall, the findings implicate the utility of mindfulness-based interventions in increasing stigma resistance among individuals with mental health problems, alleviating their psychological distress and improving overall life satisfaction.

**Behavioural Factors**

**Treatment Engagement.** Research indicates that stigma resistance may have implications on the treatment engagement of individuals with some mental health diagnoses. Cross-sectional research has been conducted in Ethiopia with a sample of individuals with diagnoses of schizophrenia (Biftu et al., 2014). In this study participants completed the ISMI (Ritsher et al., 2003) and were then categorised as showing either low or high stigma resistance, according to whether their score on the stigma resistance subscale was smaller or larger than an agreed cut-off point. Participants were asked a question about discontinuing medication (“have you ever discontinued your antipsychotic medication because of fear of stigma associated with your mental illness?”). Findings demonstrated that low stigma resistance was associated with discontinuing antipsychotic medication due to fear of stigma. Findings of this nature have important implications for practice within clinical contexts and groups supporting individuals with intellectual disabilities as they highlight that engagement with treatment may improve through interventions aimed at increasing stigma resistance. Whilst it appears that greater levels of stigma resistance may reduce the impact of stigma on treatment adherence, it is possible that increased empowerment in those higher on stigma resistance may be associated with individuals taking control over their own treatment and
medication, which for some individuals may lead to challenging the advice of professionals. The relationship between stigma resistance and treatment adherence may therefore be complex and deserves further investigation.

Social Factors

Social Engagement. In addition to outcomes at the individual level, a large body of research has highlighted the association between stigma resistance and social functioning. The study outlined above by Biftu et al. (2014) also found that low stigma resistance was associated with social withdrawal in individuals with schizophrenia, assessed using the stigma resistance and social withdrawal subscales of the ISMI (Ritsher et al., 2003). This supports the hypothesis that withdrawal from social interactions may act as a stigma reduction strategy, in supporting individuals with schizophrenia to conceal their illness from others and reduce the risk of discrimination. The researchers concluded that encouraging individuals with schizophrenia to participate in different social relationships, such as family and peer support groups and befriending projects, may support the development of greater stigma resistance.

Suggestions that stigma resistance is associated with improved social functioning were corroborated by O’Connor et al. (2018) in their secondary data analysis of individuals with schizophrenia and schizoaffective disorder. In their study, social functioning was measured using three subscales of the Quality of Life Scale (Heinrichs, Hanlon & Carpenter, 1984) that are intimately related to social functioning: Interpersonal Relations, which measures the frequency of recent social contacts, Intrapsychic Foundations, which measures qualitative aspects of interpersonal relationships, and Instrumental Functioning, which measures
vocational functioning. They found that stigma resistance, again measured with the stigma resistance subscale of the ISMI (Ritsher et al., 2003), was positively associated with social functioning across participants in these domains. Similarly, Lien et al. (2015) found a negative association between stigma resistance and social withdrawal within a mental health population, based on scores from the stigma resistance and social withdrawal subscales of the Chinese version of the ISMI (Lien et al., 2015). Interestingly, Lien et al. (2015) found stigma resistance to have the strongest correlations with the Alienation Subscale of the ISMI, which is a measure of the subjective experience of feeling less than a full member of society. This suggests that a felt sense of inferiority may underpin the social withdrawal seen within stigmatised individuals, at least in some cultural contexts.

It is important to note that a large proportion of the research that has investigated the association between stigma resistance and social outcomes has been completed with individuals with schizophrenia. Some research has highlighted the mediating role that negative and positive symptoms of schizophrenia have in the relationship between stigma resistance and social engagement. Nabors et al. (2014), in their correlational study, found negative associations between stigma resistance and both negative and positive symptoms of schizophrenia. They hypothesised that greater levels of positive and negative symptoms may increase the likelihood of an individual facing stigmatising experiences and reduce their ability to effectively cope with these experiences, making them more likely to internalise stigma. In particular, they suggested that the negative symptoms of schizophrenia may lead to social withdrawal, thereby accounting for some of the poorer social engagement seen in those with low stigma resistance. They also hypothesised that the social withdrawal seen in individuals with negative symptoms of schizophrenia may
confirm negative expectations about themselves and others, reducing an individual’s capacity to resist stigma. Despite these hypotheses, the association between positive and negative symptoms and stigma resistance has not been replicated in some studies (Biftu et al. (2014), so such explanations should be treated with caution.

Due to its correlational nature it is not possible to definitively conclude whether stigma resistance leads to greater social engagement or vice versa.

**Experienced Discrimination.** Lien et al. (2015) also found a strong negative relationship between the ISMI’s Stigma Resistance and Discrimination Experience Subscales. This suggests that increased stigma resistance may reduce the extent to which an individual perceives themselves to be discriminated against, or conversely a reduced level of perceived discrimination may increase an individual’s stigma resistance. However, Lien et al. (2015) highlighted that conflicting findings of non-association between stigma resistance and experienced discrimination have been found (Sibitz et al., 2011). Further research is required to establish whether stigma resistance does influence experienced discrimination, or if the latter is mainly influenced by other factors.

**Conclusions**

Understanding the relationship between stigma resistance and outcomes across the evidence base is important in order to aid understanding of the processes of stigma resistance, how interventions might increase stigma resistance, and the potential impact of such interventions.

Taken together, the current results based on a review of the literature indicate that stigma resistance appears to be associated with various factors with significant
functional implications: meta-cognition, emotion regulation, illness acceptance, empowerment, coping style, psychiatric symptoms, hope, insight, self-esteem, self-efficacy, quality of life, internalised stigma, treatment adherence, social engagement and discrimination experience. This has largely been studied with mental health populations, although some research has emerged in the field of obesity and irritable bowel disease. These findings point towards the conclusion that increasing stigma resistance should be a target of intervention across stigmatised groups of individuals.

Unfortunately, to date, no one has attempted to manipulate stigma resistance directly via an intervention. Instead, all research thus far is cross-sectional in nature, which means that we cannot conclude the direction of the relationship between stigma resistance and other factors. Some anti-stigma interventions which primarily aim to decrease the internalisation of stigmatising beliefs about a label/diagnosis (the process of self-stigmatisation) demonstrate promising outcomes. However, as has been highlighted, self-stigma is a distinct concept to stigma resistance. Exploration of the potential of stigma resistance as a cross-diagnostic target for therapeutic intervention that supports wellbeing and recovery is thereby warranted (Firmin, 2016b). As highlighted by Firmin et al. (2017b), more research is required to understand whether stigma resistance precedes improvement in other factors (e.g. quality of life, insight etc) or whether the factors studied are prerequisites for effectively resisting stigma, or if the relationships are indeed bidirectional.

In addition, whilst some factors like meta-cognition, psychiatric symptoms, quality of life and social engagement have been consistently demonstrated to be correlated with stigma resistance, research on other factors, such as discrimination experience, has produced more variable results, and it appears less clear whether
these factors are in fact related to stigma resistance. Firmin et al. (2016) have suggested that moderators, such as duration of the stigmatised condition, may explain unaccounted for variance between studies.

An important limitation of the current literature is that research on stigma resistance remains in its infancy. As such, further work is needed, particularly in areas where preliminary work has demonstrated interesting findings (for example the relationship between stigma resistance and emotion regulation (Raij et al., 2014)) but has not been replicated enough to examine through meta-analysis.

Another important critique of the existing literature on stigma resistance and outcomes is that a lot of the research uses a similar design, whereby participants with different stigmatising diagnoses complete self-report questionnaires that purport to measure stigma resistance and a range of other factors hypothesised to be associated with stigma resistance. Unfortunately, the majority of these studies rely on data gathered through self-report, and therefore findings are open to response bias. This is likely to be particularly important as these studies measure factors that are sensitive in nature, such as mood and stigma experiences. Replication of findings with data completed by informants as a means of triangulation may improve the validity of such findings. In addition to this, the majority of research reviewed has relied upon the ISMI (Ritsher et al., 2003) or adaptations of it for use in non-English speaking cultures. Unfortunately, research indicates that the measure has psychometric limitations; in particular research has found that the Stigma Resistance Subscale has variable to poor internal consistency. Recent research reported this subscale had an internal consistency of $\alpha = 0.55$ (Brohan, Elgie, Sartorius & Thornicroft, 2010) and $\alpha = 0.59$ (Brohan et al., 2011). This has led to the exclusion
of the subscale from some studies (Mashiach-Eizenberg, Hasson-Ohayon, Yanos, Lysaker & Roe, 2013; Park, Bennett, Couture & Blanchard, 2013). Furthermore, Firmin et al. (2017c) have argued that this measure fails to adequately reflect the construct of stigma resistance. In response to this they developed a new measure of stigma resistance, the Stigma Resistance Scale, for use with mental health populations. Initial evaluation by Firmin et al (2017c) suggests that it has good validity and reliability and reflects the concept of stigma resistance more fully through capturing the process at personal, peer and public levels. Despite this, due to the recency of its development its use to date has been limited. Furthermore, a well validated and reliable measurement tool is still required for use with other stigmatised groups.

Another difficulty related to the methodology used within the literature cited in this review lies in the quantitative nature of the research. This only allows measurement of predetermined aspects of variables and excludes the possibility of identifying factors associated with stigma resistance that may emerge from personal accounts of stigmatised individuals. Qualitative research would allow expansion of this and could allow for a more detailed understanding of outcomes associated with increased stigma resistance, grounded in the experience of individuals at risk of stigmatisation.

**Directions for Future Research**

In summary, interventions with the specific aim of targeting and increasing stigma resistance with robust evaluation designs are required in order to establish whether there is a causal relationship between stigma resistance and associated
factors. Research using a longitudinal design would allow us to understand the
direction of the relationship between stigma resistance and associated factors.

In addition to this, further development of robust measures of stigma
resistance is still required. Despite promising initial evaluation of the recently
developed Stigma Resistance Scale (Firmin et al., 2017b), further evaluation of the
scale’s validity and reliability is needed. In addition to this, these psychometric tools
have been developed for use with mental health populations, and therefore well
validated and reliable measurement tools are still required for use with other
stigmatised groups, including individuals with intellectual disabilities.

As highlighted by the review, research investigating the relationship between
stigma resistance and some factors, such as discrimination experience, remain
variable. Further investigation of the relationship between stigma resistance and
these factors would be useful. As it has been suggested that moderating variables
may account for variance between studies, it would be beneficial to further research
potential moderators of the relationship between stigma resistance and associated
factors. Further research is also required to investigate the relationship between
stigma resistance and emotion regulation, where replication of emerging findings
would strengthen understanding of the relationship.

Additionally, due to the reliance on self-report measures in most of the
existing research in the field, replication of studies looking at stigma resistance and
associated factors using informant ratings would increase the reliability of findings.
Furthermore, in order to gain a more in depth understanding of stigma resistance and
its outcomes, qualitative research exploring the experience of stigma resistance in
stigmatised populations would be beneficial and would facilitate the emergence of factors that may not be captured through pre-determined quantitative measures.

This review has highlighted that the focus of stigma resistance research thus far has been placed upon the mental health population, with a few exceptions within the physical health field. Broader understanding of the factors associated with stigma resistance is required in other stigmatised groups, such as those with other physical health problems and individuals with physical and intellectual disabilities. Due to the high levels of stigmatisation of individuals with intellectual disabilities and its negative impact upon individual and societal functioning, the need for development of interventions to target intellectual disability stigma is clear. Given the range of positive factors associated with stigma resistance in other stigmatised populations, the development and evaluation of interventions for this population with the specific aim of boosting stigma resistance is indicated.
References


Bifftu, B. B., Dachew, B. A., & Tiruneh, B. T. (2014). Stigma resistance among people with schizophrenia at Amanuel Mental Specialized Hospital Addis...


L. Montada, & M. Lerner (Eds.), *Responses to victimizations and belief in the just world* (pp. 55–63). New York: Plenum.


S. Werner (Eds.), *Intellectual disability and stigma: Stepping out from the margins* (pp. 129-147). London: Palgrave Macmillan UK.

The long-term outcomes and feasibility of assessing a psychosocial intervention aimed at increasing the capacity of people with intellectual disabilities to manage and resist stigma
Abstract

**Background:** Intellectual disability stigma is widespread and has significant negative implications for individuals with intellectual disabilities. Stigma resistance is associated with positive outcomes across stigmatised groups of individuals, and is implicated as a target for interventions tackling stigma at the intrapersonal level. However, to date there have been no interventions that seek to directly manipulate stigma resistance in individuals with intellectual disabilities.

**Aims:** The present study contributes to a multi-part feasibility and pilot study of a psychosocial intervention aimed at increasing the capacity of individuals with intellectual disabilities to manage and resist stigma. Specifically, it aimed to (1) examine the feasibility and acceptability of assessing longer-term outcomes of the intervention through (a) qualitative interviews with group members, group facilitators and significant others four months from baseline and (b) standardised outcome measures completed by group members seven months from baseline; and (2) preliminarily assess the longer-term outcomes of the intervention.

**Method:** The intervention consists of five manualised sessions delivered by facilitators of existing self-advocacy, social and educational groups for people with intellectual disabilities. Recruitment and retention rates were explored, and quantitative data assessing self-esteem, psychological distress, experienced discrimination and sense of social power were compared at baseline, intervention completion and follow-up. Qualitative interviews with group members, group facilitators and significant others were completed at follow-up and analysed using thematic analysis (Braun & Clarke, 2006).
**Results:** Assessing the longer-term outcomes of the intervention through qualitative interviews with group members, facilitators and significant others four months from baseline and standardised outcome measures completed by group members seven months from baseline was both feasible and acceptable. No statistically significant changes in scores of self-esteem, psychological distress, experienced discrimination or sense of power were found between baseline and follow-up. However, increases in self-esteem and sense of power and decreases in psychological distress and experienced discrimination, all with small effect sizes, were found. Qualitative findings demonstrated long-term benefits of the intervention for group members, facilitators and significant others. Benefits to group members indicated increases in stigma resistance at the personal, peer and public levels.

**Conclusions:** Preliminary findings of the long-term benefits of the intervention and feasibility and acceptability of the proposed methods of assessment of the outcomes indicate the appropriateness of a further controlled trial of the intervention. Recommendations for improving the feasibility and acceptability of assessing the longer-term outcomes of the intervention are made.
Introduction

Intellectual Disability and Stigma

Popular conceptualisations propose that stigma is a devalued social identity and stigmatisation is a social process that devalues individuals through conferring labels and stereotyping (Pescosolido & Martin, 2015). Importantly, stigmatisation occurs within contexts of differential social, economic and political power, which distinguish those that are ‘labelled’ and those that do the ‘labelling’ (Link & Phelan, 2001).

Stigma directed towards people with intellectual disabilities remains prevalent. Interview-based research exploring the treatment of individuals with intellectual disabilities found that stigma was an issue faced in everyday life by this group (Jahoda, Markova & Cattermole, 1988). Endorsement of statements related to personal experiences of stigma and discrimination by individuals with intellectual disabilities is common (Ali, Strydom, Hassiotis, Williams & King, 2008). A recent review of 16 studies looking at how people with intellectual disabilities view their ascribed label of intellectual disability found that the majority were aware of their ascribed label or acknowledged they are “different”; and most recognized that others view the label negatively, which was associated with feelings of shame, anger and powerlessness (Logeswaran, Hollett, Zala, Richardson & Scior, 2019).

Intellectual disability stigma can be displayed in explicit forms, for example through verbal insults (Jahoda, Markova & Cattermole, 1988) and bullying (Mencap, 2000), as well as more subtle forms which lead to a reduced quality of life for affected individuals. Stigma undermines the educational, occupational, social, physical and
emotional wellbeing of individuals with intellectual disabilities (Dagnan & Waring, 2004; Emerson and Baines, 2011; Hatton, Emerson, Glover, Robertson, Baines, & Christie, 2014; UNESCO, 2015). Importantly, people with intellectual disabilities may be more vulnerable to psychological distress resulting from stigma compared to those without intellectual disabilities, due to high levels of other social adversities experienced by this population and their reduced coping strategies and problem-solving skills (Ali, King, Strydom & Hassiotis, 2015). The damaging effects of intellectual disability stigma also have broader implications for society through increased long-term health and social care costs associated with it (Hatzenbuehler, 2009; Hatzenbuehler, Phelan & Link, 2013). Given the high prevalence of stigmatisation of this population and its significant negative impact, the need for challenging intellectual disability stigma is clear. Corroborating this, a recent government commissioned report recommended that the NHS should take more action to reduce stigma and discrimination as a means to improving the lives and health outcomes of people with intellectual disabilities (Department of Health & Social Care, 2018).

**Stigma Resistance**

A model proposed by Scior and Werner (2016) highlights the different levels which interventions addressing intellectual disability stigma should target, including the structural, interpersonal, familial and intrapersonal levels (see Appendix A). Efforts to address intellectual disability stigma thus far have been largely concentrated at the structural level, for example through the introduction of laws and policies to protect the rights of individuals with intellectual disabilities (Equality Act, 2010; United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006);
and the interpersonal level, where education and contact between individuals with and without intellectual disability have been used to challenge inaccurate stereotypes (Seewooruttun & Scior, 2014). These steps highlight a growing awareness of intellectual disability stigma.

Intrapersonal level interventions target self-stigmatisation, which is the process by which individuals in a discriminated group internalise negative stereotypes held by others into their own sense of self and identity, thus increasing their sense of being different or inferior (Corrigan & Watson, 2002). Self-stigma is associated with various negative outcomes in people with intellectual disabilities, including negative self-evaluations, negative social comparisons, symptoms of depression and anxiety (Ali, Hassiotis, Strydom & King, 2012), and decreased self-esteem (Jahoda, Wilson, Stalker & Cairney, 2010). Efforts to challenge stigma at the intrapersonal level have been developed for some highly stigmatised groups of individuals, for example, people with serious mental health difficulties (Fung, Tsang & Cheung, 2011, Luckstead et al., 2011) and people with substance abuse difficulties (Luoma, Kohlenberg, Hayes, Bunting & Rye, 2008). However, there have been no published evaluations of intrapersonal level interventions that explicitly aim to empower people with intellectual disabilities to manage and resist stigma.

Understanding how stigma may be addressed by affected individuals, at the intrapersonal level, is crucial. Two key processes, stigma management and stigma resistance, have been highlighted. Stigma management involves a stigmatised individual taking protective efforts to enable themselves to cope with the negative experience of being stigmatised and its effects, such as managing the pain and loss of opportunities resulting from stigma (Emlet, 2004). Stigma management can be
considered a passive act by this definition, and stigma management strategies such as isolating oneself and avoiding services can be viewed as both helpful and unhelpful (Miller & Major, 2000).

Stigma resistance goes beyond avoiding the impact of stigma to the use of more active attempts to create positive outcomes. It falls within an empowerment model of developing resilience, which views individuals as active participants able to create positive outcomes for themselves and others, rather than passive targets that focus exclusively on avoiding negative outcomes (Oyserman & Swim, 2001).

Knowledge of the processes involved in stigma resistance has been advanced by Firmin et al. (2017a) who proposed a conceptual model of stigma resistance from the perspective of peer support workers in recovery from serious mental health problems. In this model, resisting stigma is described at three levels; (1) the personal level, which involves not believing stigma, noticing stigmatising thoughts, educating oneself about diagnosis, maintaining recovery, and developing a meaningful identity and purpose separate from one’s diagnosis; (2) the peer level, which involves using one’s experience to help others, peer-driven service involvement and informal assistance to friends and family with difficulties; and (3) the public level, which involves public disclosure of diagnosis, educating others, advocating for others, and questioning stigma more broadly. This model provides a useful framework to guide the development of interventions targeting stigma and the capacity of individuals to resist it.

Growing evidence indicates that stigma resistance is associated with recovery outcomes, including increased meta-cognition (Firmin, Luther, Salyers, Buck & Lysakerl., 2017b; Nabors et al., 2014), emotion regulation (Raij, Korkeila,
Joutsenniemi, Saarni & Riekki, 2014), illness acceptance (Walston, 2012), empowerment (Sibitz, Woppman, Zidek & Amering., 2009), hope (Lien et al., 2015; Olcun & Altun, 2017), insight (Firmin, Luther., Lysaker, Minor & Salyers., 2016), self-esteem (O’Connor, Yanos & Firmin., 2018), self-efficacy (Lien et al., 2015; Taft, Ballou & Keefer, 2013), quality of life (Firmin, Luther, Lysaker, Minor & Salyers., 2016; Taft, Ballou & Keefer., 2012), treatment adherence (Biftu, Dachew & Tiruneh., 2014), social engagement (O’Connor, Yanos & Firmin., 2018), reduced psychiatric symptoms (Nabors et al., 2014) and experienced discrimination (Lien et al., 2015). These factors have largely been studied in the mental health population, although some research has recently emerged in the fields of obesity and irritable bowel disease. These findings point towards the conclusion that increasing stigma resistance should be a target of intervention across stigmatised groups of individuals.

**Study Rationale**

The intervention, called STORM (Standing up for Myself), aimed to address the paucity of intrapersonal level interventions targeting intellectual disability stigma by promoting the capacity of individuals with intellectual disabilities to manage and resist the impact of stigma. In view of the body of evidence linking stigma resistance with a range of positive outcomes, the intervention aimed to improve the wellbeing of individuals with intellectual disabilities and reduce the risk of self-stigmatisation and associated negative outcomes.

The Medical Research Council (2008) has emphasised that feasibility and pilot studies should form an essential step in the development, testing and adaptation of complex interventions, prior to large-scale evaluation. Feasibility testing can be defined as research completed before a main study with the aim of determining
whether the study can be carried out. It is used to estimate important parameters that are needed to design the main study, such as ascertaining feedback from peers and colleagues about the acceptability of a proposed research design. Pilot testing is where a smaller version of the main study is completed in order to test whether the components of the main study work together. It is focused on the processes of the main study, for example to ensure that recruitment, retention, treatment, and follow-up assessments run smoothly; and may involve the collection of preliminary outcome data to establish initial intervention effects and whether the data addresses the research questions adequately (National Institute for Health Research, 2015).

Development of the STORM intervention consisted of two stages. Stage One was completed in conjunction with relevant stakeholders (researchers, clinicians, and individuals with intellectual disabilities) who contributed to initial scoping of existing interventions and groups run for people with intellectual disabilities to ascertain the perceived need for this intervention, the early development of the intervention and identification of suitable measures. As such Stage One was purely addressing feasibility issues as outlined above. Stage Two, which the current study completes, comprised of both feasibility and pilot testing of the intervention and the proposed methods for evaluating the impact of the intervention. Initial feasibility of the intervention and its short-term impact was evaluated by a research team at UCL made up of my supervisor (Dr Katrina Scior), Kristina Fenn (Clinical Psychologist), Lisa Richardson (Research Associate) and Laurie Poole (Research Assistant). This stage of the research involved the piloting of the STORM intervention to a small number of groups, followed by administration of standardised outcome measures of self-esteem, psychological distress, experienced discrimination and sense of social power at baseline and intervention completion to group members; and group interviews with
group members and their respective facilitators at intervention completion. This initial evaluation established that the intervention was acceptable, its delivery was feasible and its short-term impact on stigma resistance and associated factors was promising. See Appendix B for summary of findings.

The current study aimed to build on these findings through (1) assessing the feasibility of assessing longer-term outcomes of the intervention through the use of (a) individual qualitative interviews with group members, group facilitators and participants’ significant others four months from baseline, and (b) standardised outcome measures completed by group members seven months from baseline; and (2) assessing the longer-term preliminary outcomes through analysis of data gathered from standardised measures and qualitative interviews with group members, group facilitators and significant others. Data collected as part of the current study was at the follow-up stage. The current study aimed to contribute to understanding the outcomes and mechanisms of impact of the intervention, as outlined in Medical Research Council guidance (Moore et al., 2015), which suggests that a process evaluation should clarify the pathways linking a hypothetical intervention and its causal assumptions to the outcomes produced, through developing a clear understanding of its implementation and mechanisms of impact (See Figure 1).
Research Questions

The study posed the following research questions:

1. What is the feasibility and acceptability of assessing outcomes of the intervention at follow-up?

1.1 What are the retention rates of group members completing questionnaire measures seven months from baseline?

1.2 What are the recruitment rates of group members, group facilitators and significant others completing interviews four months from baseline?

2. What is the potential long-term impact of the intervention?

2.1 Do the pilot data suggest a reduction in psychological distress and experienced discrimination and an increase in self-esteem and social power seven months from baseline? Do the pilot data suggest any evidence of unintended adverse outcomes seven months from baseline?
2.2 According to interview data, what are group members’, group facilitators’ and significant others’ perceptions of the intervention’s impact four months from baseline? Do group members, group facilitators or significant others perceive any adverse impact of the intervention four months from baseline?

It was hypothesised that (1) assessing the long-term outcomes of the STORM intervention through use of qualitative interviews with group members, group facilitators and significant others four months from baseline and completion of standardised outcome measures by group members seven months from baseline would be both feasible and acceptable to participants; and (2) the intervention would yield positive effects on participants’ levels of self-esteem, psychological distress, experienced discrimination, and sense of social power, which would be maintained at follow-up (seven months from baseline). It was hypothesised that no adverse outcomes at follow-up would be found. Finally, it was hypothesised that qualitative interview data would corroborate quantitative findings of this nature.

Method

Participants

**Intervention Participants.** 68 individuals attended at least one session of the STORM intervention. The following inclusion and exclusion criteria were applied for involvement in the intervention.

**Inclusion Criteria:**

- Participants were members of pre-existing groups for people with intellectual disabilities. The decision to work with pre-existing groups was made because
it was believed that familiarity with group members and facilitators would help provide a safe and containing environment for participants to explore potentially upsetting experiences. Furthermore, working with pre-existing groups meant that a brief intervention could be delivered without the need for additional time for group formation.

- Participants had a mild to moderate intellectual disability. The intervention was language-based and therefore inappropriate for individuals with severe intellectual disability. To ensure that participants had the required comprehension and language skills, written information and sample questions from the outcome measures were provided to facilitators during recruitment, followed by a phone call with a researcher to discuss the potential suitability of the intervention for group members.

- Participants were 16 years or older.

**Exclusion Criteria:**

- Should there be instances where some members of an existing group did not want to take part in the intervention, and there was no available time to run the intervention outside of the regular group slot, that group would 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 feel under pressure to consent to involvement in the study.

**Participants in the Quantitative Research.** Of the 68 participants who attended the intervention, 67 were included in the quantitative analysis (one participant was excluded from the quantitative analysis due to lack of capacity to consent to research involvement but attended intervention sessions following a best
interests decision making process). Demographic information was self-completed with support. Some questionnaires were only partially completed. Of the 62 participants who completed information on sex, 34 (54.8%) identified as male and 28 (45.2%) as female (five missing). In relation to age of participants, 16 (25.8%) participants were aged between 16 – 24 years, 16 (25.8%) between 25 – 34 years, 13 (21.0%) between 35 – 44 years, 10 (16.1%) between 45 – 54 years, and seven (11.3%) were aged 55 years or older (five missing). In relation to ethnicity, 51 (81.0%) participants identified themselves as ‘White British/White Other’, seven (11.1%) as ‘Black British/African/Caribbean/Black Other’, four (6.3%) as ‘Asian British/Asian Other’, and one (1.6%) as ‘Other’ (four missing). In relation to educational background, 43 (71.7%) participants attended Special Educational Needs schooling, 10 (16.7%) attended mainstream schooling, and seven (11.7%) attended both (seven missing). In relation to current housing circumstances, 36 (57.1%) participants reported living with parents or a family member, 10 (15.9%) lived alone, seven (11.1%) lived in supported living services, six (9.5%) lived with a partner, and four (6.3%) reported “other” housing (four missing). 42 participants (70%) reported that they did not have a physical disability, 15 (25%) reported they did have a physical disability, three (5%) reported that they did not know if they had a physical disability (seven missing). 36 participants (61%) reported that they did not have a sight or hearing disability, 23 (39%) reported they did have a sight or hearing disability (eight missing). 42 participants (71.2%) reported that they did not have autism, 13 (22%) reported that they did have autism, four (6.8%) did not know if they had autism (eight missing).

The sample size for this study exceeded the requirement as calculated through a priori power analysis (Faul, Erdfelder, Lang & Buchner, 2007). An effect size of
0.57 was assumed, based on prior work by Lucksted, Drapalski, Calmes, Forbes, DeForge and Boyd (2011) who piloted an intervention for internal stigma in adults with mental health issues, which produced a required sample size of 27.

**Participants in the Qualitative Research.** Of the 67 group members who took part in the research, 26 also completed interviews at follow-up. All facilitators (n=9) and seven significant others (family, friends and paid carers) of group members were also interviewed at follow-up.

**Measures**

The questionnaire used was compiled of abbreviated versions of several scales, as detailed below (See Appendix C). The amalgamated measures contained within the measures pack was given the name “Myself and the World Questionnaire”. These were used to assess the impact of the intervention on self-esteem, psychological distress, sense of power and experienced discrimination. Feedback from the stakeholder group highlighted that completion of full scales was lengthy and challenging for individuals with intellectual disabilities, therefore the scales were abbreviated and administered to group members at the same time in order to manage demands on participants, as well as time constraints of the research. However, the inclusion of a limited number of items did limit the internal consistency of each scale.

**Self-Esteem.** Three items from Dagnan and Sandhu’s (1999) version of the Rosenberg Self-Esteem Scale, adapted for use with people with intellectual disabilities, 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 ranged from 0 to 6,
with higher scores indicating higher self-esteem. The three-item scale used had acceptable psychometric properties with a Cronbach’s alpha of 0.64 at baseline, similar to the six-item version of the scale used in Dagnan and Sandhu’s (1999) study which had a Cronbach’s alpha of 0.62.

**Psychological Distress.** Seven items taken from the 14-item CORE-LD (Brooks, Davies & Twigg, 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 intellectual disabilities. 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. The three-item scale used in the current study had acceptable psychometric properties with a Cronbach’s alpha of 0.62 at baseline.

**Sense of Power.** Four items taken from the eight-item Sense of Power Scale (Anderson, John & Keltner, 2012) were administered: *I can get other people to listen to me; I can get others to do what I want; I get to make decisions; and Others pay attention to my views*. Participants were required to respond ‘never’, ‘sometimes’ or ‘always’. Possible total scores in the current study ranged from 0 to 8, with higher scores indicating greater sense of power. The Sense of Power Scale is used to identify the perception of participants’ ability to influence another person or other people. The
four-item scale used had acceptable psychometric properties with a Cronbach’s alpha of 0.67 at baseline, slightly lower than the scale in its original form which had a Cronbach’s alpha of 0.85.

**Experienced Discrimination.** Three items taken from the ten-item Perceived Stigma in People with Intellectual Disabilities Scale (Ali et al., 2008) were administered: *The way people talk to me makes me angry; People make me feel embarrassed; and I keep away from other people because they are not nice to me.* Participants were required to respond ‘never’, ‘sometimes’ or ‘always’. Possible total scores in the current study ranged from 0 to 6, with higher scores indicating a greater sense of experienced discrimination. The scale is used to measure the extent and severity of stigma that individuals with mild to moderate intellectual disabilities encounter. The three-item scale used had acceptable psychometric properties with a Cronbach’s alpha of 0.64 at baseline, slightly lower than the scale in its original form which had a Cronbach’s alpha of 0.84.

**Design**

The study used a mixed methods design. Quantitative data were collected from group members at three time points: Time Zero (baseline, a week prior to starting the intervention), Time One (intervention completion, the end of the booster session, approximately nine weeks from baseline) and Time Two (follow-up, seven months from baseline), to allow evaluation of the size of any effects and any lasting impact of the intervention. Time Zero and Time One data were collected by the research team. Time Two data were collected from all groups as part of the current study. A follow-up period of seven months from baseline was selected for collection of final quantitative questionnaire data at Time Two, allowing for approximately six months
between the final core intervention session and follow-up measure completion. This was guided by the follow-up periods used within trials of interventions that have been developed for treating anger, depression and anxiety in individuals with intellectual disabilities (Hassiotis et al, 2011; Jahoda et al, 2015; Willner et al, 2013).

Qualitative data were collected through completion of individual interviews with group members, significant others and group facilitators four months from baseline, to allow evaluation of the subjective experience of the long-term impact of the intervention and the acceptability and feasibility of the proposed methods of evaluation. It was hoped that combining direct group member reports, alongside feedback from facilitators who know the group members and the intervention in a professional capacity and significant others who know the group members in a personal capacity, would allow us to establish if the long-term impact reported by group members was corroborated by or diverged from those who observe them day to day. In this way such triangulation aimed to improve the inter-rater reliability of the study. It was agreed that significant others should be interviewed as some facilitators had minimal or inconsistent contact with group members and their understanding of any meaningful day to day impact of the intervention was therefore impaired.

Consultation with members of the steering group was completed regarding the length of the follow-up period between baseline and follow-up interview completion. Due to difficulties in memory and knowledge retention of group members it was agreed that extending the follow-up period beyond four months from baseline might result in loss of valuable feedback on the impact of the intervention and learning that may have occurred as a result. It was therefore agreed that completing interviews with group members, group facilitators and significant others four months from baseline
would allow researchers to capitalise on participant feedback regarding the breadth and depth of the impact of the intervention.

Procedure

The Intervention. The STORM intervention (see https://www.ucl.ac.uk/pals/storm) was developed drawing on narrative principles, cognitive behaviour therapy and liberation psychology. These approaches were selected as means to support individuals to consider their preferred identities, acknowledge acts of oppression against them, move in their preferred direction and problem-solve ways to overcome any barriers in doing so. Peer support (people with lived experience supporting others with similar problems) 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 change of the STORM intervention are depicted in Figure 2.
Figure 2: Hypothesised Mechanisms of Change of STORM Intervention

The intervention was fully manualised and delivered by facilitators of pre-existing groups for people with intellectual disabilities. Facilitators received brief training in the intervention and guidance on its delivery (facilitators were sent the manual to read, watched a film of one of the research team members explaining the contents and delivery of each session, and completed a phone call or in-person meeting with one of the research team members to discuss the project, suitability of participants and examples of questionnaires). Facilitators were assigned a named member of the research team who they could contact before and during delivery of the intervention for clarification of the manual. The intervention was delivered over four weekly 90 minute sessions, and a fifth booster session delivered a month after the fourth session. The intervention consisted of filmed testimonials by people with intellectual disabilities, followed by discussions and practical exercises. Different key
messages were addressed in each session. Key messages of sessions one to four were ‘My learning disability is only one part of me’, ‘It’s not ok for people to treat me badly. I don’t have to put up with it’, ‘I can stand up for myself when people treat me badly’ and ‘I can make a plan to help me stand up for myself. Talking to people I trust can help me with ideas’ and the key message for the booster session was “Things can get in the way of my plan. Talking to others can help me decide what to do next and not give up’ (See Appendix D for full summary of weekly key messages and questions). At the end of session four group members completed action plans detailing steps they would like to take following completion of the intervention, and these were reviewed in the booster session.

**Recruitment.** The study recruited from the groups who completed the STORM intervention: six self-advocacy groups, three day service groups and one college (See Appendix E for table of recruited participants). Groups were initially identified by the research team through a number of recruitment strategies. One group was identified through its involvement in the initial scoping and development phase of the intervention as its members formed part of the stakeholder group, whilst the others were identified through promotion at a Mencap Big Day Out event and via direct email contact by the research team.

When Time One measures were completed, the researcher in attendance at the session informed group members that they would be asked to consider participating in follow-up interviews and measure completion at a later stage. Following this, group facilitators were asked to contact group members to establish those willing to be interviewed four months from baseline, with a minimum recruitment target of two group members from each group. All group members who were willing to be
interviewed and able to provide informed consent were interviewed, in order to gather a broad range of feedback and maximise inclusion of individuals across variables of age, gender and ethnicity. Interviews with group members took place face to face at the base of each respective group. Interviews were conducted on an individual basis, apart from in one instance where two members of the same group requested to be interviewed together.

At the beginning of Stage Two of the feasibility and pilot testing of the study all group facilitators provided consent to complete follow-up interviews. The researcher therefore liaised with group facilitators via email or telephone to coordinate a date to complete follow-up interviews with them. These interviews were also completed face to face at the base of each respective group.

Initially, attempts to recruit significant others to be interviewed were conducted through liaison with group facilitators. Group facilitators were asked to encourage group members to pass on information sheets to their significant others detailing the nature of the study and requests for their participation in follow-up interviews (See Appendix F). This yielded no response from significant others. Therefore the recruitment strategy was altered, and group members were asked at the time of their follow-up interviews whether they could identify a significant other who they were happy to be contacted for a possible interview. In order to reduce time and expenditure, interviews with significant others took place via telephone, excluding two significant others who were interviewed face to face at their preference.

Three separate semi-structured interview schedules were developed, one for group members, one for group facilitators, and one for significant others (See Appendix G). They were developed in conjunction with the research supervisor and
refined following consultation with the stakeholder consultation group, which consisted of four individuals with intellectual disabilities. Interviews asked about memories of the intervention (group members), likes and dislikes of the intervention (group members and facilitators), long-term impact of the group (group members, facilitators and significant others), recommendations for adaptations to the intervention and procedures (group members, facilitators and significant others), and involvement in supporting group members during the intervention (significant others).

All group members who had attended the intervention were approached to complete measures at follow-up. Group members were invited by their group facilitator to attend a session at their usual group base to complete Time Two measures, and a researcher attended this session to facilitate questionnaire completion with the group. These sessions were held before or after their usual group activities, to minimise time expenditure for group members. Initial liaison between researcher and group facilitators was completed via email, and subsequent liaison regarding follow-up procedures was completed via email or telephone.

**Ethics**

The study was approved by the UCL Research Ethics Committee (Project ID Number: 0241/003, see Appendix H). All group members attending the session to complete follow-up measures were provided with an easy read information sheet that explained the purpose and content of the follow-up study. They were informed of their right to not complete the follow-up questionnaire and to withdraw their data and were asked to complete an easy read consent form. All group members, facilitators and significant others who were willing to be interviewed at follow-up were provided with information sheets and were asked to complete consent forms (See Appendix I).
Consent for audio-recording interviews was requested. Participants were able to discontinue the study at any time. In order to ensure confidentiality, names of group members completing questionnaires were anonymised through use of a coding system that allowed researchers to enter data for participants at different time points anonymously. Transcription of interview data omitted personally identifiable information including names and group membership. Questionnaire data and interview data were stored according to the General Data Protection Regulation (2016) and Data Protection Act (2018).

Another consideration in the current study was the potential risk of harm resulting from talking about sensitive topics, such as stigma and maltreatment, that forms part of the STORM intervention. It was believed that the benefit of empathic listening provided by the group facilitator and peers and the opportunity to express difficult emotions outweighed this risk (Pistrang & Barker, 2012). Group members were advised to discuss any difficulties that arose in sessions with their facilitators, significant others or a member of the research team, to minimise any negative impact of potentially challenging discussions.

Data Analysis

Quantitative Analysis. Questionnaire data were analysed using SPSS version 25. Descriptive statistics were calculated for the outcome variables across the three time points. Assumptions of normality was checked for the four abbreviated versions of the measures by visual inspection of histograms, Normal Q-Q plots and Box plots, and by calculation of skewness and kurtosis (normal distribution falling between -1.96 and +1.96). As advised by Kim (2013), numerical inspection of skewness and kurtosis was selected to most accurately assess distribution of all outcome measures. This
showed that all four measures across the three time points were normally distributed, apart from the self-esteem measure at Time One which showed a negative skew. Transformation of this variable was not completed due to the robustness of the linear mixed model (Lo & Andrews, 2015). See Appendix I for skewness and kurtosis scores of variables. Checks for outliers were completed and no outliers were identified.

Initial consideration of using a repeated measures ANOVA to analyse the data was rejected due to its listwise deletion of missing data. As the current study had a large proportion of missing data across the three time points (four missing at Time Zero, 17 missing at Time One, and 18 missing at Time Two) deletion of all participants with missing time points would have caused issues of both limited power and bias. The linear mixed model manages the issue of missing data by estimating the values of missing data, and thereby avoids the need to delete participants with missing data at any time point (Elobeid et al., 2009).

The current study used a series of linear mixed models to analyse the data collected at three time points (Time Zero, Time One, Time Two) to assess whether the intervention had any significant longer-term effects (and the magnitude of any effects) on the outcome measures. For this study a random intercepts model was used, with a variance component structure assumed. Time was included in the model as a fixed effect (Seltman, 2009). For all analyses, p values of <.05 were considered significant. As p values were not adjusted to account for the possibility of increased type I error resulting from multiple tests, p values close to .05 should be interpreted tentatively.

**Qualitative Analysis.** Qualitative data obtained from interviews with group members, group facilitators and significant others were audio recorded, transcribed
and analysed using thematic analysis (Braun & Clarke, 2006). This approach was selected as the method of qualitative analysis because the research questions regarded participants’ experiences and feelings towards the intervention, which lent themselves to an approach that facilitated the generation of themes. Due to the absence of a validated theoretical framework underpinning the programme it was decided that an exploratory analysis in which themes were derived inductively from the data, rather than a pre-established framework, was most suitable. Computerised software package NVivo Version 12 was used to support coding and theme refinement of qualitative data.

All interviews were transcribed and read several times by the researcher in order to become familiar with the data. Brief notes were completed for each interview based on initial impressions of the transcripts. Following this a process of coding was completed using NVivo, to organise participant quotations within codes. Ideas that were repeated or appeared significant were labelled and then combined to form themes. Codes were initially combined into themes within each subject group (group members, facilitators and significant others) (See Appendix L for initial themes) and then merged to represent themes across participants as a whole (See Appendix M). A hierarchy of themes made up of subthemes, intermediary themes, higher order themes and overarching themes was formed following a process of deciding how themes were connected and which were more important. Themes were reviewed against the transcripts until no new themes emerged. This process was repeated by a colleague (Trainee Clinical Psychologist) who acted as an independent rater. Differences and similarities in the themes were discussed and collaboratively refined.
**Researcher Perspective.** Good practice guidelines in qualitative research suggest researchers should clarify potential biases shaped by their personal and professional experiences, theoretical orientations, beliefs and expectations in relation to the area of research (Elliot, Fischer & Rennie, 1999). My professional experiences working with adults with intellectual disabilities within community-based services have highlighted the ways in which stigma can negatively impact upon the quality of life and mental health of adults with intellectual disabilities. My professional experience has also highlighted a need for interventions to challenge these experiences of stigma. In addition to this, at the time of my data collection findings of the early stages of the feasibility study generated by the research team demonstrated the feasibility and short-term positive impact of the intervention under investigation. It is therefore likely that the combination of these factors may have biased my views towards the potential benefits of the STORM intervention. Throughout the process of interviewing participants and analysing qualitative data I attempted to hold in mind the ways in which these experiences may create bias and maintain an objective stance as much as possible.

**Results**

**Feasibility and Acceptability of Assessing Outcomes at Follow-up**

**Retention rates of group members completing questionnaire measures seven months from baseline.** Avery et al. (2017) proposed a set of operational criteria that can be used to assess whether progression from an internal pilot study to a larger randomised controlled trial (RCT) is warranted. In their traffic light system they propose that assessing the effectiveness of an intervention’s recruitment and retention strategy is crucial to this process. Said criteria were applied to the current study in
order to inform whether to progress to a definitive trial of the effectiveness and cost-
effectiveness of the STORM intervention (Table 1).

| Table 1 |
|---|---|---|
| **Intervention Recruitment and Retention Effectiveness Operational Criteria** | **Green (Go)** | **Amber (Amend)** | **Red (Stop)** |
| Recruitment | 90-100% of target sample achieved within study recruitment periods | 70%-89% of target sample achieved within study recruitment periods | <70% of target sample achieved within study recruitment periods |
| Retention | 75%+ of participants retained for follow-up | 50%-74% retained for follow-up | <50% retained for follow-up |

Data was provided by 63 participants at Time Zero (four missing) and 50 participants at Time One (17 missing). Collected as part of the current study, 49 participants (18 missing) provided data at Time Two, seven months from baseline. The number of participants that provided data at Time Two represented 77.7% of the original sample completing data at Time Zero. Using the traffic light targets displayed above, a target of 47.5 participants was set for the completion of follow-up questionnaires, as this would represent 75% of the baseline sample. This was surpassed, and therefore retention of group members at follow-up fell within a green category according to the operational criteria identified by Avery et al. (2017),
indicating the feasibility and acceptability of assessing outcomes at follow-up, and that progression to a larger RCT using said methods is indicated.

**Session Attendance.** Decline in the proportion of group members completing questionnaire data over time, from Time Zero to Time One and from Time One to Time Two reflects an overall decline in session attendance across time. Overall attendance at STORM sessions declined as the intervention progressed, with those who did not attend across the groups increasing from eight in sessions one and two, up to nine in session three, and 13 in session four (See Figure 3).

![Group Member Attendance at STORM sessions](image)

*Figure 3: Session Attendance Graph*

**Recruitment rates for interviews four months from baseline.**

The below table (Table 2) demonstrates the targeted and achieved numbers of participants recruited for follow-up interviews.
Of the 68 group members who attended the intervention, 26 also completed interviews at follow-up. Additionally, nine facilitators (all facilitators) of the group intervention and seven significant others (family, friends and paid carers) were also interviewed at follow-up. Our initial aim to recruit two group members per group was exceeded and our aim to interview all facilitators was met. Interest and availability of group members and facilitators for interview completion at follow-up was high. Using the traffic light targets suggested by Avery et al. (2017), recruitment of group members and facilitators for follow-up interviews fell within the green category, indicating the feasibility and acceptability of assessing outcomes at follow-up through interviews four months from baseline with group members and facilitators. Progression to a larger RCT using said methods was indicated.
Recruitment of significant others to follow-up interviews was more challenging, and the strategy for this was adapted to facilitate this process. Our initial aim to recruit 10 significant others was not met. Recruitment of significant others fell within the amber category (Avery et al., 2017), suggesting that recruitment of this group should be revised before progression to a larger RCT. Reflecting on the process of recruiting significant others it appears that a lack of appropriate significant others in the lives of group members, and a lack of interest or awareness of the intervention by significant others appeared to be barriers to their inclusion at follow-up.

**Feasibility and Acceptability of Follow-up Timeframes.** An important element of the feasibility of assessing outcomes at follow-up was the timeframe proposed for follow-up. As noted earlier, the project aimed to complete follow-up interviews four months from baseline and follow-up measures seven months from baseline. Due to availability of facilitators, group members and significant others, completion of follow-up interviews ranged between four to seven months from baseline; and completion of measures for the different groups ranged between six to nine months from baseline. Table 3 demonstrates the targets and achieved timeframes for follow-up interview and measure completion. Group members and facilitators of each group were interviewed on the same day. Where significant others were interviewed, the period between baseline and follow-up interview completion has been added in brackets and marked with SO.

Streamlining the process of recruiting participants to complete interviews and measures at follow-up is required to ensure that the timeframe targets are better met in a future trial of the STORM intervention. Consistency in the researcher completing questionnaire measures with groups at each timepoint would be advised, as this would
allow the researcher to organise the date of future stages of research (the next measure completion or interviews) in person with facilitators and group members.
Table 3

**Targets and Achieved Timeframes for Follow-up**

<table>
<thead>
<tr>
<th>Group</th>
<th>Interviews</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Target Period Time Zero to Time Two</td>
<td>Achieved Period Time Zero to Time Two</td>
</tr>
<tr>
<td>Self-Advocacy 1</td>
<td>4 months</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2 X S0= 5 months)</td>
</tr>
<tr>
<td>Self-Advocacy 2</td>
<td>4 months</td>
<td>6 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(S0=6 months)</td>
</tr>
<tr>
<td>Self-Advocacy 3</td>
<td>4 months</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SO= 5 months)</td>
</tr>
<tr>
<td>Self-Advocacy 4</td>
<td>4 months</td>
<td>4 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SO=4 months)</td>
</tr>
<tr>
<td>Self-Advocacy 5</td>
<td>4 months</td>
<td>5 months</td>
</tr>
<tr>
<td>Self-Advocacy 6</td>
<td>4 months</td>
<td>4 months</td>
</tr>
<tr>
<td>Day Service 1</td>
<td>4 months</td>
<td>6 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(7 months)</td>
</tr>
<tr>
<td>Day Service 2</td>
<td>4 months</td>
<td>4 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SO=5 months)</td>
</tr>
<tr>
<td>Day Service 3</td>
<td>4 months</td>
<td>4 months</td>
</tr>
<tr>
<td>College</td>
<td>4 months</td>
<td>6 months</td>
</tr>
</tbody>
</table>
Long-term Impact of the Intervention

Change in Psychological Distress, Experienced Discrimination, Self-esteem and Social Power at Follow-up.

Mean Differences.

Table 4

Estimated Marginal Means (Standard Deviations) of Outcome Variables

<table>
<thead>
<tr>
<th></th>
<th>Baseline (Time Zero)</th>
<th>Intervention Completion (Time One)</th>
<th>Follow-up (Time Two)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Esteem</td>
<td>4.214 (1.547)</td>
<td>4.767 (1.265)</td>
<td>4.616 (1.257)</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>4.830 (2.528)</td>
<td>4.462 (3.288)</td>
<td>4.108 (3.512)</td>
</tr>
<tr>
<td>Experienced Discrimination</td>
<td>2.822 (1.456)</td>
<td>2.703 (1.720)</td>
<td>2.726 (1.824)</td>
</tr>
<tr>
<td>Sense of Power</td>
<td>5.323 (1.808)</td>
<td>5.461 (2.016)</td>
<td>5.586 (1.920)</td>
</tr>
</tbody>
</table>

The estimated marginal means demonstrate that hypotheses of reduced psychological distress and experienced discrimination and increased self-esteem and sense of power at follow-up were supported. Overall, from Time Zero to Time Two, mean self-esteem increased, although there was a slight decrease in self-esteem between Time One and Time Two, suggesting maintenance of increased self-esteem may have been somewhat challenging for group members, although scores did not revert to baseline levels. Mean sense of power scores increased between Time Zero and Time One and further increased at follow-up, suggesting that improvements in sense of power were maintained and developed following the end of the intervention.
Overall, mean psychological distress decreased between Time Zero and Time One, and had further decreased at Time Two, suggesting that improvements in psychological wellbeing were maintained and improved upon following the end of the intervention. Mean experienced discrimination scores decreased between Time Zero and Time One, but had increased again slightly at Time Two, suggesting maintenance should be considered further. This may be due to increased integration of ideas from the STORM intervention following the end of the programme, and subsequent increased perception and awareness of stigmatising experiences.

**Investigation of Statistical Significance.**

A series of linear mixed models were computed to test for intervention effects across abbreviated versions of the four scales.

A significant effect of time on self-esteem was found (F(2, 78.526)= 3.788, p=.027). Further analyses showed a significant increase in self-esteem between Time Zero and Time One and no significant change between Time One and Time Two. Analysis of the mean scores at Time One and Time Two demonstrate that there was a small decline in scores of self-esteem between intervention completion and follow-up. Analysis of the mean scores from Time Zero and Time Two demonstrate that there was an increase, although not statistically significant, in scores of self-esteem between baseline and follow-up.

No significant effect of time was found on measures of psychological distress (F(2, 69.359)=1.020, p=.366), experienced discrimination (F(2, 71.385)=0.126, p=.882) or sense of power (F(2, 74.189)=0.355, p=.702). There was therefore no significant change in scores on these measures between baseline and intervention.
completion or baseline and follow-up. Despite not reaching threshold for statistical significance it is important to note that average scores on psychological distress decreased between Time Zero, Time One and Time Two; average sense of power scores increased between Time Zero, Time One and Time Two; and average experienced discrimination scores decreased between Time Zero and Time One, before a slight re-bound effect observed at Time Two.
### Table 5

*Mean Differences of Outcome Variables*

<table>
<thead>
<tr>
<th></th>
<th>Mean Difference</th>
<th>Standard Error</th>
<th>Df</th>
<th>Significance</th>
<th>Lower Bound</th>
<th>Upper Bound</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self Esteem</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Zero- Time One</td>
<td>-.552</td>
<td>.201</td>
<td>74.964</td>
<td>.007</td>
<td>-.953</td>
<td>-.152</td>
</tr>
<tr>
<td>Time One-Time Two</td>
<td>.151</td>
<td>.177</td>
<td>64.004</td>
<td>.398</td>
<td>-.203</td>
<td>.505</td>
</tr>
<tr>
<td>Time Zero-Time Two</td>
<td>-.402</td>
<td>.230</td>
<td>96.269</td>
<td>.083</td>
<td>-.857</td>
<td>.054</td>
</tr>
<tr>
<td><strong>Psychological Distress</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Zero- Time One</td>
<td>.368</td>
<td>.433</td>
<td>68.676</td>
<td>.398</td>
<td>-.496</td>
<td>1.232</td>
</tr>
<tr>
<td>Time One-Time Two</td>
<td>.354</td>
<td>.498</td>
<td>69.501</td>
<td>.480</td>
<td>-.640</td>
<td>1.347</td>
</tr>
<tr>
<td>Time Zero-Time Two</td>
<td>.722</td>
<td>.512</td>
<td>88.653</td>
<td>.162</td>
<td>-.296</td>
<td>1.740</td>
</tr>
<tr>
<td><strong>Experienced Discrimination</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Zero- Time One</td>
<td>.119</td>
<td>.246</td>
<td>74.250</td>
<td>.628</td>
<td>-.370</td>
<td>.609</td>
</tr>
<tr>
<td>Time One-Time Two</td>
<td>-.024</td>
<td>.273</td>
<td>65.848</td>
<td>.932</td>
<td>-.568</td>
<td>.521</td>
</tr>
<tr>
<td>Time Zero-Time Two</td>
<td>.096</td>
<td>.282</td>
<td>88.621</td>
<td>.735</td>
<td>-.465</td>
<td>.657</td>
</tr>
<tr>
<td>Sense of Power</td>
<td>Time Zero - Time One</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------------------</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Time Zero - Time One</td>
<td>-.138</td>
<td>.286</td>
<td>71.645</td>
<td>.632</td>
<td>-.708</td>
<td>.433</td>
</tr>
<tr>
<td>Time One - Time Two</td>
<td>-.126</td>
<td>.291</td>
<td>72.031</td>
<td>.667</td>
<td>-.706</td>
<td>.455</td>
</tr>
<tr>
<td>Time Zero - Time Two</td>
<td>-.263</td>
<td>.313</td>
<td>96.834</td>
<td>.402</td>
<td>-.885</td>
<td>.358</td>
</tr>
</tbody>
</table>
Subjective perceptions of the intervention’s impact four months from baseline. Experiences of the intervention converged and differed across group members, facilitators and significant others. For this reason qualitative data were analysed separately within these three subject groups. Overarching themes emerged from the data, each reflecting different questions relating to the intervention’s impact. Within overarching themes several higher order themes and intermediary themes emerged. Themes are presented below and quotations are provided to illustrate each. Quotes are labelled with GM for group members, F for facilitators and SO for significant others, followed by a label for the type of group: SA for self-advocacy, DS for day service and C for college. Frequency counts have been included, demonstrating the number of times that each theme, higher order theme and intermediary theme were endorsed. Within each table N is noted to represent the number of participants endorsing each theme and subtheme.

Group Member Recollections of the Intervention. At follow-up interview, group members were asked what they remembered of the intervention. Whilst this does not directly answer the research question it is highly relevant in understanding the impact of the intervention, as very limited recollection of the intervention at follow-up may indicate minimal long-term impact. Two overarching themes were identified: task based memories and relational based memories.
Table 6

**Group Member Recollections of the Intervention - Thematic Analysis**

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Higher Order Themes</th>
<th>Intermediary Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task Based Memories (n=26)</td>
<td>Videos (n=19)</td>
<td>Intellectual Disability (n=4)</td>
</tr>
<tr>
<td></td>
<td>Group Discussions (n=18)</td>
<td>Bullying (n=15)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Responses to Maltreatment (n=9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Action Plans (n=4)</td>
</tr>
<tr>
<td>Relational Based Memories</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n=4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Task Based Memories**

All group members that were interviewed recalled elements of tasks that were completed as part of the intervention.

**Videos.** The most frequently recalled element of the intervention was the use of videos to highlight key messages and ideas. Recall of the content of these videos was quite vivid for a significant number of group members.

“We were watching the DVD. The bloke went on the bus, he was a bit nervous going on the bus and then they were picking on him. Then he didn’t go out, he was staying indoors, he was a bit nervous going out.” (GM, DS)
Group Discussion. A large proportion of group members also recalled their involvement in group discussions related to different elements of the intervention.

“All these things we spoke about. That people don’t understand people with learning disabilities. A lot of people are ignorant.”

(GM, SA)

A number of group members recalled discussions held about the nature of intellectual disabilities, and what this diagnosis meant in relation to their self-perception.

“We talked about what a learning disability was. I knew lots of stuff anyway, but I got a little bit from that, what it means to me.”

(GM, DS)

A large number of group members recalled discussions about their own and others’ experiences of being bullied.

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

(GM, SA)

A large proportion of group members also recalled discussing various responses available to them in instances of maltreatment. Based on group member recall it appeared that these discussions were largely facilitated by the video material where individuals with intellectual disabilities spoke about negative treatment and their subsequent actions. Some group members made reference to the option of standing up for themselves in response to maltreatment, whilst others recalled discussions about the importance of utilising sources of support when responding to maltreatment.
“We looked at other people that’s got disabilities and how they overcome their disabilities. One guy, something happened to him and he decided to stay at home instead of coming out. In the end he overcame it.” (GM, SA)

“We talked about how to stick up for ourselves, like say if someone said something to you, not in a very good way.” (GM, SA)

“We spoke about how we could talk to someone about it.” (GM, DS)

**Action Plans.** Several group members recalled their completion of action plans, identifying tasks and goals that they would like to complete following their involvement in the intervention.

“We spoke about these sheets we had to fill in...We did one that said “what do I want to try?”” (GM, SA)

**Relational Based Memories**

A small but significant number of group members talked about the relationships that were strengthened over the course of the intervention sessions.

“I remember about the STORM group that a lot of people at first I thought “I don’t know them” but now I do know them.” (GM, SA)

**Impact of Intervention on Group Members**

Six overarching themes were identified in relation to the impact of the STORM intervention on group members (See Table 7).
### Table 7

**Impact of Intervention on Group Members - Thematic Analysis**

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Higher Order Themes</th>
<th>Intermediary Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developed Understanding and Insight (GM n= 21; F n= 5; SO n= 2)</td>
<td>Improved Understanding of Intellectual (and other) Disabilities (GM n= 16; F n= 2; SO n=1)</td>
<td>Challenging Myths (F n=1)</td>
</tr>
<tr>
<td></td>
<td>Awareness of the Treatment of People with Intellectual Disabilities (GM n= 15; F n= 2; SO n= 1)</td>
<td>Signs of Bullying (GM n=2)</td>
</tr>
<tr>
<td>Improved Connection with Others (GM n=19; F n= 5; SO n= 5)</td>
<td>Strengthened Within-Group Connections (GM n=16; F n= 5; SO n=1)</td>
<td>Shared Experience (GM n=4; F n= 2; SO n=2)</td>
</tr>
<tr>
<td></td>
<td>Increased Confidence in Social Situations (GM n=3; F n= 8; SO n= 5)</td>
<td>Increased Contribution to Group (GM n= 4; F n= 2; SO n= 1)</td>
</tr>
<tr>
<td>Drive for Advocacy (GM n= 19; F n= 6; SO n= 2)</td>
<td>Enhanced Self-advocacy (GM n= 18; F n= 4; SO n= 2)</td>
<td>Involvement in Advocacy Initiatives (GM n=8; F n= 4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Refined Skills in Self-advocacy (GM n=6; SO n= 2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Empowerment (GM n=5; F n= 9; SO n= 5)</td>
</tr>
<tr>
<td>Increased Activity (GM n=9; F n= 2; SO n= 2)</td>
<td>Increased Standing Up for Others (GM n=5; F n= 1)</td>
<td>Greater Consideration for Others (GM n=8; F n= 2)</td>
</tr>
<tr>
<td>Managing Difficult Emotions (GM n=4; F n= 3)</td>
<td>Raised Independence (GM n= 4; F n= 2; SO n= 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Exploring Past Experiences (GM n=3; F n= 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reduced Self-blame (GM n=2; F n= 3)</td>
<td></td>
</tr>
<tr>
<td>Differential Impact (GM n=3; F n=4)</td>
<td>High Levels of Pre-existing Advocacy (GM n=3; F n=3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative Impact (GM n=7; F n=2)</td>
<td></td>
</tr>
</tbody>
</table>

101
Developed Understanding and Insight

The most commonly endorsed theme was the development of group members’ understanding, knowledge and insight in relation to various topics as a result of the intervention.

Improved Understanding of Intellectual (and other) Disabilities. Some group members said that their understanding of the nature of intellectual disabilities had increased following the intervention, which connects with the aim of the first session of the STORM intervention which explores what an intellectual disability is and what this means for group members.

“I’d say I have more of an understanding about learning disabilities and how it affects people.” (GM, C)

A parent of one group member referred to an incident indicating his son’s increased curiosity and interest in understanding the nature of an intellectual disability following the intervention.

“He asked me “what is a learning disability?”. I tried to explain it, but I think it’s [the intervention] normalised it. I thought he must have got this from the group. He’s always known from quite a young age that he’s got a learning problem, learning difficulties. But I think it’s good that he’s got that self-awareness in a way.” (SO, SA)

Some group members reported that the intervention had also led to a heightened interest and understanding of individuals with other disabilities, and mental/physical health issues. One group member expressed an increased interest in
meeting those with various difficulties as a route to improving her understanding of the experiences of others.

“I want to know how it feels having it, because I’ve never experienced what mental health is like or being in a wheelchair or being schizophrenic or being Cerebral Palsy or anything like that. I thought putting myself in their shoes, then I would actually know and know how to help other people.” (GM, DS)

One facilitator highlighted that an increased knowledge of those with other difficulties led to the debunking of inaccurate and unhelpful stereotypes about others.

“The group had a lot of myths around Downs Syndrome, even though they’ve got members with Downs Syndrome in their group. We could challenge some of those.” (F, SA)

**Awareness of the Treatment of People with Intellectual Disabilities.** A large number of group members, facilitators and significant others referred to the increased understanding of the negative treatment of people with intellectual disabilities that group members had developed through the intervention, and ways in which this echoed or contrasted with group members’ own experiences.

“I think looking at the videos, at what other people have been through, and how it affects them, you realise you’re not the only one in that situation sometimes.” (GM, SA)

“I’m quite confident in myself, but other people in my group are not. Then in the group they were saying they get pushed out of a queue, that people were pushing into them and making them wait longer, and I thought that would not
happen. So it did surprise me. There were things that I thought were better, but actually it opened my eyes if that makes sense.”

(GM, SA)

Relating to the treatment of people with intellectual disabilities, a number of group members expressed that their understanding of the signs of bullying and discrimination had increased due to the intervention.

“[I’m] just better at looking out for the signs of people bullying and getting bullied.”

(GM, SA)

Improved Connection with Others

A large number of group members reported that the intervention had helped to improve their relationships with others, both within and outside of the group. This was a theme also acknowledged by facilitators and significant others.

“I was glad to be with the group because I don’t always spend time with people outside [the group], so sometimes it’s quite interesting to see what other people say.”

(GM, SA)

Strengthened Within-Group Connections. Some group members, facilitators and significant others noted that relationships within the STORM groups had been strengthened due to involvement in the intervention and increased time spent together.

“I kind of wondered whether it was the STORM project or just the fact that people were getting together; because what happened was the group used to meet but not that frequently and actually coming for a weekly meeting seemed to work really well in terms of supporting each other better and kind of
friendships developing within that group in a way that wasn’t happening so much before.” (F, SA)

“He’s definitely been more on his iPad. Facebooking and texting various people that I think he knows from the group.” (SO, SA)

An aspect that facilitated the strengthening of connections within the group, which several group members, facilitators and significant others referenced, was the sense of a shared experience between group members who had faced similar experiences and difficulties, which appeared to have a normalising effect.

“You can empathise as well, because you are in the same situation, more or less. They also find it hard when they report problems or sometimes they get let down as well.” (GM, SA)

“I think for a lot of them it’s like “it just happens to me, no one cares about me” and then they see, well it’s not just you. Not to diminish what they’re going through but to see it as a wider, it’s a very big problem, so in that kind of respect it has kind of broadened their awareness. It’s like “so now you know it’s not just you, you know there are other people you can speak to who will understand what you’re going through.” (F, SA)

Group members, facilitators and significant others also reported that relationships within the group had been improved as a result of an increase in group members’ ability to share personal experiences and opinions.

“When I first come here I was quiet, but now I got to know them and that’s it. I talk more.” (GM, SA)
**Increased Confidence in Social Situations.** Group members spoke about their increased confidence and engagement with people beyond the group context following the intervention. Facilitators and significant others commented on their observations of improved confidence of group members within social contexts.

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

**Drive for Advocacy**

An overarching theme in group members’, facilitators’ and significant others’ accounts was the increased drive of group members to advocate for their own and others’ needs following the intervention.

“I feel more confident, and that it’s alright to speak up for myself and speak up for others.” (GM, SA)

**Enhanced Self-advocacy.** The majority of group members said that following the intervention they felt more able to speak up and make their views known. This was also echoed by feedback from facilitators and significant others.

“I absolutely love the STORM group so much because I think it’s good to get your voice out, as in speaking up for yourself. You’ve got to stand up and be firm for yourself.” (GM, SA)
“I think something I seem to have noticed since then [the intervention] is that he’s a lot more confident. And he does sort of stick up for himself a bit more than he did before.” (SO, SA)

Following the STORM intervention several groups implemented advocacy initiatives, to allow group members to raise public understanding of the appropriate treatment of people with intellectual disabilities. Some of these initiatives included material taken directly from the STORM intervention, whilst others appeared to be underpinned by the ideas of the intervention.

“What we’re doing now is going into schools to tell them that we actually get bullied and all that. I feel good about that. [We tell them] they shouldn’t bully us, take the mickey.” (GM, DS)

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

For a number of group members, participation in the intervention allowed them to consider and practice ways of standing up for themselves in an effective and assertive manner, avoiding previously unsuccessful ways which had involved passive or aggressive attempts to stand up for themselves.

“STORM made me more confident just by feeling like you’re alright, there’s nothing stopping you, provided you do it in the right way. You can’t go off and swear at them, but if you do it in the right way and the right manner there’s nothing wrong with standing up for yourself. If you go off swearing at them and being abusive then that’s where you get yourself into a lot of trouble. But if
you just say to them “actually you need to leave me alone because I have got disabilities”.” (GM, SA)

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

“We did have a situation at work where he felt that he had been bullied by one of the other staff members and he did actually go to another member of staff and say “this man is not being nice to me”. And that was all looked into and they’ve dealt with it which has been good. So he was able to make his case and not just sit there and take it. He wouldn’t have been assertive like that before. He would have come home and moaned to me and I might have had to say something.” (SO, SA)

Alongside an increased ability to stand up for oneself, group members also identified a shift in their personal sense of confidence and ability to bring about positive changes in the attitudes and behaviour of others through their advocacy efforts. This increased sense of empowerment had also been noticed by facilitators and significant others.

“It makes me feel that we can change something if you stand up for yourself. Hopefully some authorities might listen.” (GM, SA)

**Increased Standing Up for Others.** A large number of group members spoke of their increased desire and ability in advocating for and helping others in need due to the intervention. These attitudinal and behavioural changes had been noticed by
facilitators also.

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

(GM, SA)

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

(F, SA)

In addition to increased advocacy for others, group members reported more general feelings of increased empathy and consideration for others following the intervention. Facilitators had also recognised this increased care towards others shown by group members.

“I learnt to be considerate to others. Listen to what others say.” (GM, SA)

An interesting outcome reported by group members and facilitators alike was that involvement in the intervention had increased group member reflection on their own behaviour towards others and had at times highlighted their own capacity to bully or stigmatise others.

“I think what the programme did...I mean it was focussing very much on being part of a community and community members maybe bullying our guys [group members]. But on the flip of that, it was also very good at reminding our guys that they can be bullies too. And we’ve had quite a few issues in terms of their use of social media and appropriate use of social media. But it was good that
we had the STORM programme that we could say “Hold on a minute. You’re behaving in this way but what have we learnt here?”” (F, DS)

Increased Activity

Increased activity levels following the intervention, in terms of social engagement and hobbies, were highlighted by many interviewees as a key outcome of the intervention.

“I go out more. I’ve been going round my nan’s a lot.” (GM, DS)

In particular, several group members and facilitators were aware that the skills and confidence gained by group members from involvement in STORM had led to other achievements and projects.

“I’ve just done a three week course [NVQ], just recently finished, and I passed it, I got all my certificates. I was so overwhelmed with myself. I just can’t get my head around it. That course wasn’t easy, it was kind of like STORM. I honestly do think it [STORM intervention] has helped, because with the STORM project I think I gained more experience, because I was low in confidence, I sort of re-built up my confidence by doing STORM and then moved onto doing something completely hard I didn’t think I’d ever pass. But I managed to pass, through STORM.” (GM, SA)

“She [group member] was wanting to do some more art and get involved in things. I mean some of the stuff that has been happening, like the newsletter course, it has been something that I think actually might not have been something she would have done before the course, but actually she saw it as
being a possible step on from STORM, because she was quite keen to do some
more activities in the daytime and that was one of the things that came up as
being possible.”

(F, SA)

Raised Independence. Underpinning this increased activity, it appears that the
independence levels and sense of self-efficacy of group members increased following
the intervention. This was corroborated by facilitators and significant others.

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

(GM, DS)

Managing Difficult Emotions

A key outcome of the intervention that was referenced by a large number of
group members and facilitators was its role in facilitating the expression and
processing of difficult emotional content, and the benefits of doing so.

“It was good to be able to talk and sit down and say our feelings, be able to
talk to other people, you know.”

(GM, SA)

Exploring Past Experiences. Some group members and facilitators reported
that the intervention had allowed the exploration of events from the past that had
previously not been discussed or fully addressed.

“It got everybody to talk and we talked about some quite in-depth stuff. Some
people started saying some stuff from school. So it opened my eyes in that
way.”

(GM, SA)

Reduced Self-blame. Other group members expressed that the intervention
had reduced self-blame and guilt surrounding their negative treatment. This was
confirmed by facilitators.

“I think it helped me to move on. I think because I learnt it wasn’t my fault I was bullied, and I think that’s what I’d been thinking, because it’s how I am, but I’ve realised it wasn’t. And because I’ve been doing this it’s taught me “ok, people are mean to people, but it’s not your fault, it’s them, it’s not you”. I think I’ve learnt that doing this, doing STORM.”

(GM, C)

Differential Impact

A number of group members and facilitators observed that the type and extent of the impact of the intervention varied across participants.

**High Levels of Pre-existing Advocacy.** Group members and facilitators often highlighted that the extent of the impact of the intervention was dependent upon the pre-existing levels of advocacy of group members. Individuals with high levels of pre-existing confidence in asserting themselves reported that the programme had less impact on them or it served the function of consolidating ideas that were already known to them, rather than developing new knowledge or ideas.

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

(GM, SA)

“People had already put in place some systems to cope with discrimination, stigma. Particularly as they are of a certain age group. I think that by their age, I think they are all in their early 50s or 60s, they have some way of dealing with discrimination, because these are people that have been going on
to have children, to marry, to have some kind of jobs. So it was a way for them to reflect on what was working for them and what was not working and how it was benefitting them.” (F, SA)

**Negative Impact.** Whilst no sustained adverse outcomes of the intervention were identified by group members, facilitators or significant others, some group members and facilitators did report short term negative emotional responses following some of the videos. Some group members reported that they experienced confusion in response to some videos due to the speed of verbal delivery, whilst several group members and facilitators reported that the nature of some videos left individuals feeling upset.

“It [the video] was like quite difficult, fast, he was talking fast. That was quite bad. A lot of people didn’t like that one.” (GM, DS)

“If I’m honest, I think some of those videos, it hasn’t been a lasting effect, but those sessions were hard. I think it just depends on what support you get doesn’t it, or how you are emotionally, on how you deal with that. But from a professional point, I think the balance was good, but we did give a lot of support around those videos.” (F, SA)

**Impact of Intervention on Facilitators**

Although not directly asked about the impact on themselves as facilitators, six facilitators spoke of the benefits of the programme for themselves, summarised under two overarching themes: increased understanding of group members and development of group protocols.
**Increased Understanding of Group Members.** A large proportion of facilitators (n=5) spoke about the impact that the intervention had upon their own understanding of group members’ experiences and described their subsequent closer connections with group members.

“I thought they're well accepted within their community, but actually once we got together I thought “oh actually you have experienced”, so actually for me that was an eye opener, that I learnt from that in that sense. I already know the guys anyway, but it was really nice to get to know them on a whole other level as well and explore those issues with them. Makes our working relationship better.”

(F, DS)

**Changes to Group Protocols.** Several facilitators (n=3) reported that a key outcome from the intervention had been the integration of STORM intervention ideas or materials into existing protocols for their group, which had supported the development of existing groups and services.

“I’ve embedded some of STORM into the curriculum and I’d really like to keep it there because we have got a strand on dealing with problems, and within that we do teach people to stand up for themselves, but there needs to be more work around that. We need to improve our curriculum, develop that a little bit more.”

(F, C)

“He [Trainee Policeman] was on a 4 day placement...and when he saw the clip [from STORM session 2] of the mother and daughter who’d experienced hate crime but hadn’t had the response they wanted from the police, his reaction was pretty full-on. They have to write a response which comes back to
us, in terms of what they’ve learnt when they were with us and what they enjoyed; and the thing he focussed in on was that video and how he would take that back. What we’re now doing for any future placements that we get, we now make sure that those placements have access to that video clip because it had such an impact on this particular individual.”

(F, DS)

Impact of Intervention on Significant Others

Although not directly asked about the impact on themselves, three significant others spoke of the benefits of the intervention for themselves. One overarching theme was identified in relation to the impact of the STORM intervention on significant others: reduced carer responsibility.

Reduced Carer Responsibility. Three parents highlighted the burden of responsibility of caring for an individual with intellectual disabilities, and that the possibility of issues of stigma and discrimination being addressed by others outside of the family reduced the pressure within families to be the sole protectors of their sons and daughters.

“It’s always nice if somebody comes in and talks to them and makes them understand, it’s nice really. I know we do it but it’s hard work for us, but if it comes from somebody else I think it makes it a lot easier.”

(SO, SA)

One parent also highlighted the value of addressing issues of stigma and discrimination outside of the family home due to the difficulty that some families have in exploring these issues.
“It’s something he needs to talk about in a group because he won’t necessarily want to talk to me about it.” (SO, SA)

**Discussion**

**Feasibility and Acceptability of Assessing Outcomes at Follow-up**

The study demonstrated promising results in relation to the feasibility and acceptability of assessing the long-term outcomes of the intervention through qualitative interviews with group members, group facilitators and significant others at follow-up and standardised outcome measures completed by group members at follow-up. Difficulties of completing follow-up interviews and measures within the intended timeframes emerged for several groups; this should be addressed as a priority in any further evaluation of the intervention.

Retention rates of group members completing outcome measures at follow-up was good, and recruitment of group members and facilitators to interviews at follow-up was also feasible. Recruitment of significant others to follow-up interviews was more problematic and requires further consideration to improve the feasibility of this aspect of the research process. Requesting the group members’ consent in person to contact their significant others and obtaining significant others’ contact details from them directly appears to improve the recruitment of significant others. The option of obtaining consent and contact details earlier, perhaps at the point of intervention completion, may maximise the recruitment of significant others.

Group member recollection of the intervention at follow-up was variable. Whilst all group members demonstrated recall of tasks completed within the intervention, in particular watching videos, recall of other key elements of the
intervention such as key discussions, creating action plans and developing connections within the group were less frequent. As demonstrated by some quotes presented here, recall of the intervention at follow-up was limited or vague for several group members. It is possible that reducing the follow-up period for interviews to less than three months may allow for a greater retention of the intervention and improved quality of group member feedback.

**Impact of Intervention**

Findings reflected the positive long-term impact of the intervention from the perspective of group members, significant others and facilitators. Quantitative data demonstrated a significant increase in self-esteem between baseline and intervention completion. Unfortunately between intervention completion and follow-up there was a small decline in self-esteem, which meant that overall there was no significant change in self-esteem from baseline to follow-up, meaning the positive impact of the programme on self-esteem was not maintained long-term to a statistically significant extent. However, it is important to note that analysis of the estimated marginal means demonstrates that from baseline to follow-up, mean self-esteem and social power increased, whilst psychological distress and experienced discrimination decreased.

These findings were corroborated by qualitative assessment which highlighted the positive impact of the intervention. For group members, positive effects included developing understanding and insight around intellectual disability and the treatment of people with intellectual disabilities, increased levels of activity and social engagement, an opportunity to process difficult emotions and past experiences, improved connections with others both within and outside of the intervention setting, and an increased drive for advocating for self and others. An interesting and
unexpected finding was an increased awareness among group members into their own behaviour towards others and their potential to mistreat others. Benefits to facilitators and significant others of the intervention also emerged. Facilitators highlighted positive changes to their group protocols and their own understanding of group members, and significant others highlighted that addressing stigma outside of the home context reduced their sense of responsibility as carers. Group members and facilitators highlighted that the intervention appeared to have differential impact on group members, according to each individual’s pre-existing confidence in standing up against stigma. No evidence of unintended long-term adverse outcomes was found at follow-up. However, group members and facilitators highlighted the short-term negative impact of some of the videos used in the intervention, which some group members found temporarily confusing or upsetting.

Findings from the current study supported initial results regarding the immediate impact of the intervention reported by Kristina Fenn (Clinical Psychologist). These demonstrate enhanced stigma resistance among group members following the intervention, as highlighted in group interviews at Time One where they acknowledged acts of oppression, affirmations of stigma resistance, plans to resist stigma and educate others, and increased empowerment and confidence. Results from the current study corroborate these themes and provide evidence that the acknowledgement of acts of oppression, affirmations of stigma resistance and increased empowerment and confidence continue to be found at follow-up. Plans to resist stigma and educate others have been acted upon through involvement in various advocacy initiatives and everyday actions where group members have advocated for their own and others’ needs.
The current study supports and builds on the existing literature on stigma resistance. Findings of the study demonstrate that targeting stigma resistance can apparently lead to outcomes that fit within the three levels proposed in the conceptual model of stigma resistance by Firmin et al. (2017a). At the personal level, the current study demonstrated that the intervention led to increased insight about group members’ own labels of intellectual disability. It also supported the expression of negative emotional material and thoughts that may have negatively affected group members’ wellbeing. Additionally, the intervention supported the pursuit of meaningful purpose through its impact on increased activity levels and social integration. At the peer level, the intervention allowed group members to reflect on shared experiences of maltreatment, and several group members noted that this sense of shared experience served as a means to support one another, reduced the internalisation of stigma, and build more meaningful relationships. At the public level, involvement in the intervention led to increased advocacy of their own and others’ needs and rights by group members, and a range of initiatives aimed at educating others about intellectual disability and treatment of people with intellectual disabilities. The current findings expand on the conceptual model proposed by Firmin et al. (2017) by identifying some of the factors impacting on an individual’s capacity to resist stigma, for example pre-existing levels of advocacy.

Study Limitations

The key target of the STORM intervention was the strengthening of stigma management and resistance. Unfortunately, to date there is no validated measure of self-stigma or stigma resistance for people with intellectual disabilities, and therefore only associated outcomes could be measured in the current study. In addition to this,
the study had a small sample size, therefore all conclusions drawn from this feasibility study must be interpreted with caution. It is possible that the sub-sample of individuals interviewed may have been biased, as it is likely that group members, facilitators and significant others who opted to be interviewed were more motivated or held more positive attitudes towards people with intellectual disability asserting their equal status and rights than those who did not respond to requests for an interview.

In addition to this, as interviews were completed by myself, it is possible that participants felt a need to express positive views on the intervention due to my role as a member of the research team.

**Implications and Further Study**

Results from the current feasibility study suggest the long-term positive impact of the STORM intervention and the feasibility and acceptability of assessing the impact of the intervention through completion of follow-up interviews and measures at the proposed time scales. This highlights the suitability of completing a larger scale RCT of the intervention in the future.

Experiences of conducting the current feasibility study are informative for tailoring the design of further evaluation. The current study found that recruitment to interview was relatively straightforward for group members and facilitators. However, further consideration of early and targeted recruitment of significant others is required. Additionally, the timing of follow-up interviews with group members may require further consideration to maximise group members’ memory of the intervention.

On a broader scale, the current study, in combination with the feasibility study as a whole, demonstrates the potential benefits of interventions targeting stigma
resistance to people with intellectual disabilities. This points to the opportunity of other researchers within the intellectual disability field to develop interventions with a similar goal.

Whilst the current study attempted to target the lack of interventions addressing intellectual disability stigma at the individual level, there remain few interventions at the familial level which target intellectual disability stigma (Scior & Werner, 2016). The development of interventions for families, carers and significant others aimed at supporting them in challenging stigmatising beliefs about intellectual disability may be particularly helpful for individuals with more severe intellectual disabilities who were excluded from the current programme and would be unlikely to benefit from intrapersonal level interventions requiring verbal communication. This would be beneficial in expanding the wealth of interventions targeting intellectual disability stigma across the levels at which it exists.
References


*Data Protection Act 2018* (USA).


Part Three: Critical Appraisal
Introduction

This critical appraisal will cover some key issues that arose for me during the empirical study. These issues are divided into three sections. The first will describe the assumptions of the research and how my understanding of these has changed throughout the research process. The second section will cover some of the methodological issues that I encountered. The final section offers a reflexive exploration of my professional experiences and the way in which these shaped my attitudes as a researcher. It will also cover the personal impact of my involvement in the study.

Research Assumptions

The STORM intervention aimed to achieve several psychological and behavioural benefits in the group members attending, including improved self-esteem, reduced psychological distress, increased self-efficacy in rejecting prejudice, reduced negative reactions to self-stigma and increased social power. One of the anticipated routes underpinning the desired changes was through supporting group members to acknowledge acts of oppression against them and actively resist these acts (See Figure 1). In this way, the STORM intervention drew on ideas taken from liberation psychology, an approach which emphasises the role of human rights and social equity in collective and individual wellbeing (Watts & Flanagan, 2007). Liberation psychology proposes that through exposing social injustice, creating fair societies, promoting self-determination and ending oppression, emotional healing can occur (Prilleltensky, 2003). As hypothesised, the long-term outcomes identified through interviews with group members at the follow-up stage indicated that the intervention had increased their awareness of the behaviour of others directed
towards them, improved their understanding of stigma and discrimination, and advanced their efforts to challenge these experiences and advocate for fairer treatment. Interestingly though, the interviews suggested that involvement in the intervention had also supported group members to reflect on their own behaviour towards others, and the ways in which they themselves may be the perpetrators of discrimination and stigmatisation. Reflecting on this unanticipated outcome, it is possible that this may be related to the increased sense of social power resulting from the intervention. Sense of social power refers to a person’s perception of their ability to influence others (Galinsky, Gruenfeld & Magee, 2003). An increased sense of social power may have led participants to an increased understanding of the impact of their own behaviour on the wellbeing of others. The significance of this is likely compounded by the increased empathy of group members resulting from discussing the impact of maltreatment.

Figure 1: Hypothesised Mechanisms of Change of STROM Intervention
It was also hypothesised that peer support would be an important part of the intervention, with hypothesised benefits for wellbeing and reductions in self-stigma in line with benefits found in other populations (Pistrang, Barker & Humphreys, 2008). Peer support can be defined as persons with lived experience of mental health problems and recovery supporting others with lived experience. It is an empirically validated resource promoting recovery (Priebe, Omer, Giacco & Slade, 2014). Its application to interventions for individuals with intellectual disabilities appears helpful. Salmon (2013) found that in some teenagers with intellectual disabilities, connecting with other young people with intellectual disabilities allowed sharing of stigma experiences and a greater sense of belonging; this in turn created a viable strategy for creating sustainable friendships. Interestingly, improved relationships appeared to be one of the most important outcomes of the STORM intervention. Improved connection with others was the second most frequently endorsed subtheme in the qualitative study, with 16 group members referring to strengthened connections within the group during their interviews. Many group members, facilitators and significant others pointed to the sense of shared experience that was highlighted within the intervention, with group members discussing and reflecting on similar life experiences. This in turn facilitated strengthened connections. This result supports the importance of peer support within the STORM intervention and highlights the centrality of this therapeutic paradigm to the intervention’s success.

Methodological Issues

Several issues arose throughout the research process that caused challenges to the integrity of the research design and these warrant further consideration due to plans to further test the intervention in a cluster-randomised feasibility trial. The first challenge was the difficulty of recruiting significant others to be interviewed at the
follow-up stage of the trial. The initial strategy in which group members were asked to pass on information sheets to their significant others, requesting their inclusion in interviews, was unsuccessful. Subsequent changes made to the recruitment strategy, whereby group members were directly asked at their follow-up interviews for their consent to contact their significant others and, where consent was given, for the contact details of significant others, was more successful. Despite this change in protocol the initial recruitment target for significant others was not met. Reflection on this issue has led to possible ideas which may strengthen future recruitment. Pursuing the more direct process of asking group members in person for consent to contact their significant others appears helpful and should be pursued. It could also be beneficial to begin recruitment at an earlier stage of the trial, perhaps in session 4 or the booster session, to allow several weeks to contact and agree a suitable time to speak with significant others. It is also possible that providing significant others with more information about the STORM intervention could be helpful in recruiting them to interviews.

Reflecting on the interviews with significant others, it is apparent that many had little to no knowledge of the intervention before being interviewed. Some significant others declined involvement in interviews due to their lack of knowledge of the intervention. This is an issue requiring careful consideration, as there are benefits and disadvantages to increasing the involvement of significant others in the intervention. When asked at interview whether they would have liked to be more involved in the STORM intervention, some significant others said this would have been helpful in allowing them to continue relevant discussions at home and offer any practical or emotional support needed. In contrast, others reported that they respected the autonomy of the group member they supported and believed that the extent of
their involvement should be determined by group members themselves. Certainly, respecting the autonomy of group members and empowering them to take action for themselves is central to the ethos of the STORM intervention, and perhaps provides a rationale for maintaining the same level of significant other involvement moving forward.

**Reflexive Exploration**

Reflexivity addresses the reciprocal influence between the researcher on the one hand, and the research process, findings and participants on the other (Hofmann & Barker, 2017). It entails consideration of potential biases in an individual’s personal and professional experiences, theoretical orientations, beliefs and expectations in relation to the area of research (Elliot, Fischer & Rennie, 1999) and how these may impact on, and be impacted by, the research process.

My professional experiences, working with adults with intellectual disabilities within community-based services, have highlighted the ways in which stigma can negatively impact the quality of life and mental health of adults with intellectual disabilities. My professional experience has also highlighted a need for interventions to challenge these experiences of stigma. In addition to this, at the time of my data collection findings of the early stages of the feasibility study had been completed by the research team and demonstrated the feasibility and short-term positive impact of the intervention under investigation. Furthermore, throughout my involvement in the current research I attended seminars held by the UCL Unit for Stigma Research, through which I built an awareness of an array of stigma research being completed which highlighted stigma interventions and the positive outcomes associated for individuals across clinical populations. It is therefore likely that the
combination of these experiences may have created bias in my views towards the benefits of the STORM intervention, and of stigma resistance interventions more broadly.

The current research was informed by a critical realist approach, which recognises that whilst a “true” reality does exist, there are multiple interpretations of reality which are constructed and inextricable from our perspectives and experiences. These interpretations effect what is “observable” to each individual, however unobservable structures also effect observable events (Archer, Bhaskar, Collier, Lawson & Norrie, 1998). Such a stance sits between a positivist approach to research which relies purely on observable facts to reveal reality independent of a researcher (Wilson, 2010), and the phenomenological approach which proposes that no “true” reality exists, instead the world is subjectively socially constructed through the researcher’s perspectives and experiences (Easterby-Smith, Thorpe & Jackson, 2008). In the current research there is an assumption of the truth that all participants attended the STORM intervention, however there is an acknowledgment that each individual’s experience of the intervention will vary, and my interpretation of participant’s reporting of the intervention will also be influenced by my own experiences, beliefs and interactions with each participant. I have attempted to minimise my role in applying personally biased meaning to participant reports of the intervention through making attempts to create non-biased dynamics within both the questionnaire sessions and interviews, however there was still an interaction between myself and participants which likely constructed a certain interpretation of the experience of the intervention studied.

One means of safeguarding against imposing one’s personal biases on the research process is through ‘bracketing’, in which a researcher attempts to explore in
detail and then ‘bracket’ or suspend their assumptions, while holding them in awareness (Fischer, 2009). Within my research this felt particularly important within the interview completion and analysis process. Throughout the process of interviewing participants and analysing qualitative data, I attempted to hold in mind the ways in which my professional experiences may have made me biased and offer an objective stance as much as possible, through bracketing. Explicitly building in questions into the interview schedule about participant dislikes of the intervention and any adverse outcomes as a result of the intervention sought to address the risk of recall of purely positive elements of the intervention. I also read interview transcripts and considered which issues I tended to follow-up and those I neglected during the interviews. The process of discussing and refining themes during the analysis process with an independent rater also helped me gain a balanced view of the data and ensure I was attending to the negative content alongside the data which spoke positively of the intervention. I was also aware of making attempts to bracket my assumptions within the questionnaire measure completion sessions. Within these sessions I attempted to read questionnaire items in a non-leading way, and where clarification was sought from group members I was mindful of phrasing answers in a way that did not encourage them to answer favourably in relation to their experience of the intervention. Despite these attempts, the ability to entirely bracket one’s beliefs has been recognised as almost impossible and instead the approach proposed by Finlay (2008) is that researchers should attempt to reach a balance between bracketing one’s beliefs and using them as a source of insight.

Throughout the research process I was also aware of the potential impact of my clinical training, particularly the way in which this might affect interactions within the semi-structured interviews. This issue became particularly pertinent
during times when group members spoke about experiences of stigmatisation that had negatively impacted their mood or self-perception. I endeavoured during these times to hold in mind the differing objectives of the research interview as opposed to a clinical interview. Overall I attempted to remain quite close to the interview schedule during interviewing, to ensure that my desire to offer therapeutic help following personal disclosure was minimised, however there were times when in the interests of building rapport I found myself highlighting participants’ strengths or validating their emotional and behavioural responses to past experiences in a way that might have been more suited to a clinical setting. Despite experiencing some conflict between my clinical and researcher roles, I also found my clinical skills useful during the research process. As a clinician with experience of working therapeutically with individuals with depression, anxiety and trauma, I felt able to explore the emotional impact of participants’ difficult experiences and manage the impact of discussing highly emotive content on participants.

Reflecting on my relationship to the research completed, I am aware of its impact on me as both an individual and professional, beginning my clinical psychology career. At an individual level, engaging with the personal narratives of group members who have been directly affected by intellectual disability stigma, and the significant others and group facilitators who have been indirectly affected by it, has strengthened my belief in challenging discrimination and stigma seen in everyday life across stigmatised populations. At a professional level, witnessing the benefits of the STORM intervention has strengthened my resolve to facilitate the empowerment of people with intellectual disabilities through my work. Upon qualification I intend to work within community learning disability services, and from this research I will take forward an increased awareness of the ongoing barriers
people with intellectual disabilities face in life and a heightened interest in challenging these barriers at different levels. Drawing on the multi-level model of intellectual disability stigma interventions proposed by Scior and Werner (2016), I hope that through my role as a clinical psychologist I will be able to target intellectual disability stigma at an individual, familial and organisational level through direct therapeutic and consultation work, and at the societal level through engaging with community psychology principles to shape policy, legislation and public discourse.

Conclusions

The prevalence and harmful impact of intellectual disability stigma makes it a highly important area of research. This study has provided new insight into a promising intervention targeting the management and resistance of intellectual disability stigma at the intrapersonal level. As part of the initial feasibility and piloting study of the intervention it has highlighted the potential long-term outcomes of the intervention, as well as areas in which its evaluation is limited and could be developed further. Involvement in the research has enhanced my motivation to challenge intellectual disability stigma on a personal and professional basis.
References


Hofmann, M., & Barker, C. (2017). On researching a health condition that the researcher has also experienced. *Qualitative Psychology, 4*(2), 139-148.


Appendices

Appendix A: Multi-level Model of Intellectual Disability Stigma Change Interventions (Source: Scior & Werner, 2016)
Appendix B: Summary of Research Findings reported by Kristina Fenn.

Extract taken from discussion section of thesis.

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.
Appendix C: Questionnaire Measure

V22

Myself and the World Questionnaire

Private and Confidential

You don’t need to write your name on this form.

The researchers will keep your information private and confidential

Research Code: .................. Group Code: ............. Researcher: ...................... Date: ......................

TIME TWO / T3
### Example

<table>
<thead>
<tr>
<th>I watch sports on TV</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
</table>

### Section 2 - About how you see yourself

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I feel that I have a lot of good qualities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 I am able to do things as well as other people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 I like myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 I try to hide my learning disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 The way people talk to me makes me angry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Never</td>
<td>Sometimes</td>
<td>Always</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----------</td>
<td>--------</td>
</tr>
<tr>
<td>People make me feel embarrassed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I keep away from other people because they are not nice to me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section 3- About how much control you feel you have in your life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can get other people to listen to me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can get others to do what I want</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get to make decisions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others pay attention to my views</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 4- Over the last week

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 Have you felt really lonely?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Have you had difficulty getting to sleep or staying asleep?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Have you threatened or shouted at someone?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 Have you felt unhappy?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 Have you felt people are getting at you?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 Have you bottled up angry feelings?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 5

There are lots of ideas about what people with learning disabilities can and can’t do. We are interested in your views.

**Example**

<table>
<thead>
<tr>
<th>I think politics is boring</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
</table>

I think most people with learning disabilities…

<table>
<thead>
<tr>
<th>19  …will achieve very little in life</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>20  …should let others make decisions for them</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>21  …shouldn’t have romantic relationships</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
</table>
Because I have a learning disability…

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>22 I don’t try to achieve things</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23 I let others make decisions for me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 I shouldn’t have romantic relationships</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Programme Summary

| Session 1: | What does ‘learning disability’ mean to people with learning disabilities?  
| What does it mean to me? |
|---|---|
| **Key message:** My learning disability is only one part of me. |

<table>
<thead>
<tr>
<th>Session 2:</th>
<th>How are people with learning disabilities treated?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key message:</strong> It’s not OK for people to treat me badly. I don’t have to put up with it.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Session 3:</th>
<th>How do people with learning disabilities respond to being treated negatively?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key message:</strong> I can stand up for myself when people treat me badly.</td>
<td></td>
</tr>
</tbody>
</table>

| Session 4: | What am I already doing when others treat me in a way I don’t like?  
| What else do I want to try? |
|---|---|
| **Key message:** I can make a plan to help me stand up for myself. Talking to people I trust can help me with ideas. |

1 month later...

<table>
<thead>
<tr>
<th>Booster Session:</th>
<th>Actions plans for Session 4 - What worked and what got in the way?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key message:</strong> Things can get in the way of my plan. Talking to others can help me decide what to do next and not give up.</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix E: Participating Groups and Participants

<table>
<thead>
<tr>
<th>Group type</th>
<th>Organisation name</th>
<th>Group name</th>
<th>No. of participants (male, female)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-advocacy</strong></td>
<td>Inclusion Project</td>
<td>SA1 / Pilot group</td>
<td>5 (3, 2)</td>
</tr>
<tr>
<td></td>
<td>People First</td>
<td>SA2</td>
<td>7 (4, 3)</td>
</tr>
<tr>
<td></td>
<td>Mencap</td>
<td>SA3</td>
<td>10 (5, 5)</td>
</tr>
<tr>
<td></td>
<td>Mencap</td>
<td>SA4</td>
<td>9 (5, 4)</td>
</tr>
<tr>
<td></td>
<td>Learning Disability</td>
<td>SA5</td>
<td>5 (2, 3)</td>
</tr>
<tr>
<td></td>
<td>Care Alliance</td>
<td>SA6</td>
<td>5 (2, 3)</td>
</tr>
<tr>
<td></td>
<td>People First</td>
<td>SA7</td>
<td>5 (4, 1)</td>
</tr>
<tr>
<td><strong>Day Service</strong></td>
<td>Inclusion Project</td>
<td>DS1</td>
<td>10 (8, 2)</td>
</tr>
<tr>
<td></td>
<td>Mencap</td>
<td>DS2</td>
<td>4 (2, 2)</td>
</tr>
<tr>
<td></td>
<td>Choice Support</td>
<td>DS3</td>
<td>8 (4, 4)</td>
</tr>
<tr>
<td><strong>College</strong></td>
<td>Special Educational Needs</td>
<td>C</td>
<td>5 (2, 3)</td>
</tr>
</tbody>
</table>

| Total               |                         |                           | 68 (38, 30)                       |
Appendix F: Information Sheet and Consent Form for Significant Others

Standing Up For Myself Follow-up - Study Information

About the project

- 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.
- We have developed a new psychosocial group programme called Standing Up for Myself (STORM), to help people with learning disabilities cope with and stand up to the stigma they often have to face on account of having a learning disability.
- As the identified relative or carer of an individual who has taken part in the STORM programme, you may be aware that they have recently completed the programme. You may have already received information about this, but just in case we have enclosed a copy with this letter.
- We are testing the feasibility of running this programme and evaluating its impact on people with learning disabilities.

What can you do as the family or carer of a group member?

- In order to understand the impact of the programme, we want to collect some information from the people who know group members well. As a relative or supporter of a group member we are requesting your involvement in this.
- This will involve a brief telephone conversation (approximately 30 minutes) with a researcher from University College London (UCL) about your opinions of the programme and whether it has affected the group member in any way. The key topics we would like to discuss with you include:
  - How do you think the programme has affected the group member you know?
  - Have you noticed any changes in how the group member feels about themselves?
  - Have you noticed any changes in how the group member interacts with other people?
  - Has the group member’s behaviour changed since completing the programme?
  - Has the group member become involved in any new activities since completing the programme?
Have you noticed any adverse effect of taking part in the programme on the group member?

Does the group member ever talk to you about the programme or what was discussed in the programme?

- Interviews will be audio recorded, so that the researcher can refer back to the discussions. We hope to complete these conversations approximately 2 months from the final session of the programme, however the exact date of this can be arranged according to your availability. All information you share with the researcher will be anonymised so that your feedback cannot be linked to you personally.

- We will also be completing interviews with group members. We have produced separate information sheets for group members, requesting their involvement in this stage of the research.

- We will also be asking group members to complete a follow-up questionnaire in approximately 5 months.

- We would ask that you support group members to consider taking part in the interviews and questionnaire.

  All group members and family/carers who complete these interviews will be offered £5 vouchers as a token of appreciation.

- Please indicate on the following ‘Consent Form’ if you would be happy to take part in an interview.

- If you would be happy to be contacted by the research team, please complete your contact details.

- If you do not wish to be contacted, please tick the box indicating that you do not wish to be contacted.

- We will ask group facilitators to collect this form from group members in their next session.

If you have any questions about being involved in this research, please contact Rebecca Cooper (Trainee Clinical Psychologist, UCL) at:

Telephone- 02076 791 845 Email- Rebecca.cooper.16@ucl
Consent Form (Significant Others Version)

Please write the name of the group member that you know below:

........................................................................................................................................

Please tick to indicate whether you are happy to take part in an interview for feedback on the STORM programme:

Yes, I would like to take part in an interview

No, I do not want to take part in an interview

Sign: ________________________________ Date: __________________________

If you are happy to be contacted by the research team, please complete your contact details below:

Name................................................................................................................................

Phone Number..................................................................................................................

Email Address..................................................................................................................

My preferred method of contact is (circle one):  Telephone | e mail

Thank you for taking the time to complete this form!

Please ensure that the group member you know returns this to their group facilitator in time for their next session.
Appendix G: Interview Schedules

Interview Guide for Group Members

Confirm consent has been provided to be interviewed and recorded

Ensure recorder turned on

1. **Looking back on STORM**

*What do you remember about the STORM group?*

Possible Prompts:

- What did you talk about?
- What did your group do?
- What did you like about STORM?
- What didn’t you like about STORM?

2. **Impact of STORM**

*Has STORM helped you change anything?*

Possible Prompts:

- Did you learn anything new?
- Do you do anything differently now?
- Do you feel differently now? (About yourself? About other people?)
- Has it changed how you get on with people?
- Has it changed how confident you feel about standing up against prejudice?
- Did STORM make anything better for you? If yes, how is it better? How did STORM make it better?
- Did STORM make anything worse for you? If yes, how is it worse? How did STORM make it worse?

3. **Action**

*Did you make an action plan at the end?*

Possible Prompts:
• What did it say?
• Did you do anything in the action plan? If yes, what did you do?
• Anything you haven’t done? If so, what made it difficult?
• What do you think about your action plan now?

4. Overall Recommendations

Would you tell other people with learning disabilities take part in the STORM group?

Possible Prompts:

• Would you tell a friend to take part in STORM?
• Why would you say yes or no?
Interview Guide for Group Facilitators

Confirm consent has been provided to be interviewed and recorded

Ensure recorder turned on

1. Impact of STORM

Of course, this may be very different for different individuals, but what, if any, impact do you think STORM had on group members?

Possible Prompts:

- Do you feel that STORM made anything better for group members? If yes, in what way? How did STORM make this happen?
- Do you feel that the group members learnt anything new from taking part in STORM?
- Have you observed any changes in the group members as a result of STORM? What changes?
- Have you noticed any changes in the things that group members are now doing?
- Have you noticed any changes in the confidence or mood of group members?
- Have you noticed any changes in the way that any group members interact with other people?
- Did STORM have any negative impact on any group members? If yes, in what way? How did STORM make that happen?

2. Action

Have group members completed anything from their action plans?

Possible Prompts:

- Have the group members been able to do any of the things they wrote about in their action plans? Which things?
- Were there any things they haven’t done? If so, what have been some of the difficulties with doing these?

3. Overall Recommendations

Would you suggest to colleagues in your own or other organisations to run a STORM group?
Possible Prompts:

- Would you advise a colleague in your own or another organisation to run a STORM group?
- If yes, why would you recommend it? If no, what are the reasons you would not recommend it?
Interview Guide for Significant Others

Confirm consent has been provided to be interviewed and recorded

Ensure recorder turned on

Establish the name of the group member that the significant other is connected to, and their relationship to the group member. Add the name of group member to below prompts.

1. Establishing awareness of STORM

What do you know about the STORM programme?

Possible Prompts:

- Were you given an information sheet about STORM at the beginning?
- If yes, was this useful? Did it provide the right sort of information? Anything that was missing or unclear?
- If no, would you have liked to receive information about the programme?

2. Looking back on STORM

Did (group member name) talk to you about STORM at all?

Possible Prompts:

- What did they say?
- Did they ask for your help or support with anything arising from the sessions?
- How much support did you provide to (group member name) during the STORM programme?

3. Impact of STORM

What, if any, impact do you think STORM had on (group member name)?

Possible Prompts:

- Do you feel that (group member name) learnt anything new from taking part in STORM?
- Have you observed any changes in (group member name) as a result of STORM? What changes?
• Have you noticed any changes in the things that (group member name) is now doing?
• Have you noticed any changes in the confidence or mood of (group member name)?
• Have you noticed any changes in the way (group member name) interacts with other people?
• Did STORM lead to any other positive changes? If yes, in what way? How did STORM make this happen?
• Do you feel that STORM made anything worse for (group member name)? If yes, in what way? How did STORM make that happen?

4. Action

Has (group member name) taken any action following the STORM programme, based on what was covered in the programme?

Possible Prompts:

• Are you aware if STORM helped him/her to do anything new? What did it help them to do? How did STORM help them to do that?
• Are you aware of what (group member name) wrote about in their action plan? Are you aware of whether they have been able to do any of the things they wrote about in their action plans? Which things? Were there any things they haven’t done? If so, what have been some of the difficulties with doing these?

5. Overall Impressions of STORM

What is your overall opinion of the STORM programme?

Possible Prompts:

• Do you have any opinions on the STORM programme?
• Do you think the way STORM is run with a clear focus on the group, but information provided to significant others to ensure they know what is going on and can support the person if needed, is appropriate?
• Is there anything about the STORM programme that you would change?
Appendix H: Ethical Approval Form

UCL RESEARCH ETHICS COMMITTEE

Amendment Approval Request Form

<table>
<thead>
<tr>
<th>1</th>
<th>Project ID Number: 0241/003</th>
<th>Name and Address of Principal Investigator: Dr Katrina Scior, Research Dept of Clinical Educational &amp; Health Psychology, (JCL, Gower Street, London WC1E 6BT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Project Title: Development of a psychosocial intervention designed to enhance the capacity of people with intellectual disabilities to manage and resist stigma (CONTEST)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Type of Amendment/s (tick as appropriate)</td>
<td>- Research procedure/protocol (including research instruments) - Consent form/s</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Participant group - Other recruitment documents - Information Sheet/s</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Sponsorship/collaborators - Principal researcher/medical supervisor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Extension to approval needed (extensions are given for one year)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Information Sheet/s - Consent form/s</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Other recruitment documents - Principal researcher/medical supervisor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Extension to approval needed (extensions are given for one year)</td>
</tr>
</tbody>
</table>

*Additions to the research team other than the principal researcher, student supervisor and medical supervisor do not need to be submitted as amendments but a complete list should be available upon request.
Justification (give the reasons why the amendment/s are needed)
Having completed a pilot of the STORM programme we found that some of the feedback we wanted to capture about experiences of the programme were covered during the final 'booster session' of the programme (where participants discuss progress and barriers for their individual action plans). Given this we are seeking not to repeat any questioning during a follow up feedback session and instead seek agreement (from facilitators and group members) to record the booster session. Any questions topics not covered during the booster session discussions would later be prompted by the researcher and we would also seek to audio record this too, with everyone’s agreement.

We would ask to record any telephone or in person interviews with group facilitators, again subject to their agreement.

If anyone declines to be audio recorded, in the booster session or during any feedback sessions then detailed notes would be taken instead.

As noted in our previous application for an amendment, during the follow up stage of the research we will invite a sample of the participants who had completed the programme to take part in an interview. To aid the interview process and analysis, we will seek to audio record these interviews. Individual interviews will only be conducted with people who are happy for these to be recorded and this will be made clear in advance at the point of seeking interest in participating in an interview.

Finally, we are also seeking to complete interviews with a sample of 'significant others' such as family or paid carers. This would need to be someone that the person knows well and who is aware of the person taking part in the STORM programme. This aspect of the evaluation has been added to enrich the experiences of the person to see whether others in their life notice any positive or negative effects of them having taken part in the programme. At times carers would also have a role in the feasibility of programmes such as STORM as they would facilitate people with learning disabilities to attend or support them with aspects of their action plans, as such it is important that we are able to capture this feedback. We would also seek to audio record these interviews.

All group members, significant others and group facilitators that complete individual interviews at the 3 month follow up stage will be offered a £5 voucher, to incentivise participation.
### Details of Amendments

(Provide full details of each amendment requested, state where the changes have been made and attach all amended and new documentation)

Audio record the booster session, feedback sessions, individual interviews with facilitators, significant others and any follow up interviews with agreement. In addition, as a lot of detail regarding impact of the intervention gets discussed in the Booster session, with group members’ consent we would like to audio record the Booster sessions. Wherever group members aren’t happy with us recording the booster session and/or feedback we will take careful notes and refrain from recording.

Individual interviews at follow up with group participants will only be conducted with people who are happy for these to be audio recorded. This will be made clear in advance at the point of seeking interest in participating in an interview.

(See Info Sheet for Group Members Version 2 attached)

Information sheet for group facilitators has been amended to include recording of telephone interview (attached).

For interviews with significant others we would initially ask the group member who took part in the programme about their wishes, they would have a discussion with their facilitator whether they are happy for a member of the research team to carry out this interview with their chosen significant other and written consent from the group member will be obtained. The group member would then be provided with information to pass onto their significant other, which includes a consent form and contact information request (see Information Sheet for Significant Others). These forms would be returned to the group facilitator and sent onto the research team along with the consent form from the group member.

All individuals (group members, significant others, group facilitators) who complete individual interviews at 3 month follow up stage will be offered a 25 retail voucher, to incentivise participation.

### Ethical Considerations

(Insert details of any ethical issues raised by the proposed amendment/s)

Audio recording may make people feel uncomfortable and therefore reluctant to participate in the booster session, which could lead to them not receiving the full benefits of the programme. Researchers will seek agreement of everyone to audio record this part of the group programme and will monitor comfort levels and ascent throughout. Where people do not wish the session to be audio recorded their wishes will be respected and instead detailed notes will be taken. Individual discussions with facilitators would also only be recorded upon agreement.

For individual interviews with group members or significant others in the follow up phase of the research, only people who agree to being audio recorded will be engaged in an interview.

Group members may not want a researcher to speak with a significant other. There will be no obligation for group members to recommend a significant other for an interview and this will be made clear in the information sheets. Consent will be obtained from the person and only significant others for whom we have a corresponding consent form for a group member would be contacted for an interview. (See ‘Consent to sig other’ attachment).

Interviewing significant others may potentially raise difficult topics around experiences of stigmatisation and discrimination of both themselves and the group member they are connected to. These may lead to distress in significant others. To address the risk of this we will ensure that significant others are supported to reflect on any difficult emotions raised by the interview at the end of the interview. Furthermore, it is hoped that discussion in interviews will provide significant others with the opportunity to share and explore these experiences; and contribute to the development of ways to prevent the impact of these negative experiences on others which could be seen as a way to utilise these experiences in a constructive and empowering way. It is therefore felt that the benefits of completing interviews with significant others outweigh the risks of not completing them.

Offering a financial incentive could potentially leave individuals feeling under pressure to take part in the research. Offering financial incentive has been proposed in order to facilitate recruitment to the follow up stage of the research, which has the risk of being challenging due to the time period that will have passed since end of running the STORM programme. Financial incentive will therefore facilitate completion of this
stage of the research. Informed consent will be sought by the research team to ensure each potential participant is happy about their involvement in the research and that they are also informed they can withdraw at any time.

Other Information (provide any other information which you believe should be taken into account during ethical review of the proposed changes) n/a

Declaration (to be signed by the Principal Researcher)

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendments to be implemented. • For student projects I confirm that my supervisor has approved my proposed modifications.

Signature: [signature]
Date: 21 11 2017

FOR OFFICE USE ONLY:

Amendments to the proposed protocol have been approved by the Research Ethics Committee.

Signature of the REC Chair, Professor John-Feretqan
Date: 28/11/2017
Appendix I: Information and Consent Forms

Group Member Easy Read Information Sheet

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

We are the research team:

Katrina  Lisa  Rebecca  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.

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

You have now finished the STORM programme.

This letter will give you information about what research we would like to do next and what we would like you to do if you want to take part.

You can talk about it with other people like your family and group members 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

Now that you have finished the programme we want to see if it helps people in the future

About the research

In 2 months we would like to meet with you to discuss how you feel and your opinions about the programme

In 5 months we would like 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 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 need 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

Your opinions can help us make the programme better

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
You can contact Katrina Scior:

Email: K.Scior@ucl.ac.uk

Phone: 0207 679 1845

We will do our best to sort out the problem
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 and recorded?

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: ________________________________

______________________________________________________________
Facilitator Information Sheet and Consent Form

Standing Up For Myself Follow-up - Study Information

About the project

• As you are aware, we have developed a new psychosocial group programme called **Standing Up for Myself (STORM)**, to help people with learning disabilities cope with and stand up to the stigma they often have to face on account of having a learning disability.
• 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.
• We are testing the feasibility of running this programme and evaluating its impact on people with learning disabilities.

Current stage of the project

• As you have completed the delivery of the STORM programme we would now like to evaluate the long-term impact of the programme on people with learning disabilities.
• To do this, we would like to speak to group members, group facilitators and significant others (family/carers of group members) in order to understand their opinions of the programme and whether it has affected group members in a lasting way. We would also like group members to complete the ‘Myself and the World’ questionnaire again.

What will I need to do as a group facilitator?

Brief telephone interview with you

• Complete a brief telephone interview (approximately 30 minutes) with a researcher from UCL, to explore your opinions of the programme and whether it has affected the group members in any way.
• These telephone interviews will be audio recorded, so that the researcher can refer back to what has been discussed.
• We hope to complete these interviews approximately 2 months from the date of the booster session, however the exact date of this can be arranged according to your availability.
• All information you share with the researcher will be anonymised so that your feedback cannot be linked to you or any group members.

Individual interviews with group members

• We will also be completing interviews with group members approximately 2 months from the date of the booster session.
• We have produced separate information sheets requesting their involvement in this stage of the research.
• We would request that you support us at the Booster session to ask group members to take part in the interviews. We will inform you if and when group members are being interviewed, in case they need any additional support from you around this time.

Interviews with significant others

• We would also like to complete some interviews with significant others of group members who attended a STORM programme (e.g. family, partners or paid carers). This would also be approximately 2 months from the date of the booster session.
• At the booster session you will be given information for the group member and significant other. We would ask that you speak to group members individually to discuss the interview with a significant other to see if they have someone they would be comfortable with a researcher speaking to.
• The group members will be asked to complete a form to indicate whether they consent to us contacting their significant others for an interview. We would ask that you support the person to return this to us (it can be scanned and e mailed or posted).
• Group members that give consent will be provided with an information sheet to be passed onto their significant other. The significant other will be asked to indicate on this sheet whether they wish to be contacted and provide their contact details. This form should be returned to you, via the group member.
• We would like your assistance in checking if group members have a form to return, to collect them within two weeks of the booster session and scan/send the form to us along with the persons consent form.

All group members, group facilitators and significant others who complete these interviews will be offered £5 vouchers as a token of appreciation.

Group completion of the Myself and the World questionnaire

• 5 months after completing the booster session we are requesting that group members complete the ‘Myself and the World’ questionnaire again. We
would like your assistance to bring together group members in order to complete this questionnaire.

What will happen next?

Rebecca Cooper (Trainee Clinical Psychologist, UCL) who is responsible for this phase of the project will be in contact with you shortly to arrange a suitable time to complete the telephone discussion.

However, if you have any questions about your involvement in this part of the research, please do not hesitate to contact her at:

Telephone- 02076 791 845    Email- Rebecca.cooper.16@ucl.ac.uk
**Consent form for Facilitators**

I agree to take part in an interview with Becky Cooper as part of the continuing evaluation of the STORM programme.

I agree to my interview being audio recorded.

I agree to support group members individually to consider whether they would like Becky Cooper to speak to a significant other and to identify who this might be. I will send their written decision to Becky Cooper.

I agree to support the research team by collecting information from significant others and sending this to Becky Cooper.

I agree to support the research team at the Booster session to consider whether group members would like to take part in individual interviews.

Where needed I will help facilitate Becky Cooper making contact with group members to arrange interviews.

I understand that I can contact the research team at any time if I have any concerns/queries.

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

180
Significant Other Information Sheet and Consent Form

Standing Up For Myself Follow-up - Study Information

About the project

• 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.
• We have developed a new psychosocial group programme called Standing Up for Myself (STORM), to help people with learning disabilities cope with and stand up to the stigma they often have to face on account of having a learning disability.
• As the identified relative or carer of an individual who has taken part in the STORM programme, you may be aware that they have recently completed the programme. You may have already received information about this, but just in case we have enclosed a copy with this letter.
• We are testing the feasibility of running this programme and evaluating its impact on people with learning disabilities.

What can you do as the family or carer of a group member?

• In order to understand the impact of the programme, we want to collect some information from the people who know group members well. As a relative or supporter of a group member we are requesting your involvement in this.
• This will involve a brief telephone conversation (approximately 30 minutes) with a researcher from University College London (UCL) about your opinions of the programme and whether it has affected the group member in any way. The key topics we would like to discuss with you include:
  ❖ How do you think the programme has affected the group member you know?
  ❖ Have you noticed any changes in how the group member feels about themselves?
  ❖ Have you noticed any changes in how the group member interacts with other people?
  ❖ Has the group member’s behaviour changed since completing the programme?
  ❖ Has the group member become involved in any new activities since completing the programme?
❖ Have you noticed any adverse effect of taking part in the programme on the group member?
❖ Does the group member ever talk to you about the programme or what was discussed in the programme?

- Interviews will be audio recorded, so that the researcher can refer back to the discussions. We hope to complete these conversations approximately 2 months from the final session of the programme, however the exact date of this can be arranged according to your availability. All information you share with the researcher will be anonymised so that your feedback cannot be linked to you personally.
- We will also be completing interviews with group members. We have produced separate information sheets for group members, requesting their involvement in this stage of the research.
- We will also be asking group members to complete a follow-up questionnaire in approximately 5 months.
- We would ask that you support group members to consider taking part in the interviews and questionnaire.

**All group members and family/carers who complete these interviews will be offered £5 vouchers as a token of appreciation.**

- Please indicate on the following ‘Consent Form’ if you would be happy to take part in an interview.
- If you would be happy to be contacted by the research team, please complete your contact details.
- If you do not wish to be contacted, please tick the box indicating that you do not wish to be contacted.
- We will ask group facilitators to collect this form from group members in their next session.

If you have any questions about being involved in this research, please contact Rebecca Cooper (Trainee Clinical Psychologist, UCL) at:

**Telephone- 02076 791 845  Email- Rebecca.cooper.16@ucl**
Consent Form

Please write the name of the group member that you know below:

........................................................................................................................................

Please tick to indicate whether you are happy to take part in an interview for feedback on the STORM programme:

Yes, I would like to take part in an interview

No, I do not want to take part in an interview

Sign: __________________________ Date: ______________________

If you are happy to be contacted by the research team, please complete your contact details below:

Name................................................................................................................................

Phone Number..............................................................................................................

Email Address..............................................................................................................

My preferred method of contact is (circle one): Telephone | e mail

Thank you for taking the time to complete this form!

Please ensure that the group member you know returns this to their group facilitator in time for their next session.
## Appendix J: Skewness and Kurtosis Scores

<table>
<thead>
<tr>
<th></th>
<th>Kurtosis</th>
<th>Skewness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Value</td>
<td>Standard Error</td>
</tr>
<tr>
<td>Time Zero Psychological</td>
<td>0.208</td>
<td>0.608</td>
</tr>
<tr>
<td>Psychological Wellbeing</td>
<td>0.821</td>
<td>0.662</td>
</tr>
<tr>
<td>Time One Psychological</td>
<td>-</td>
<td>0.496</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>0.618</td>
<td>0.668</td>
</tr>
<tr>
<td>Time Zero Self-Esteem</td>
<td>-</td>
<td>0.711</td>
</tr>
<tr>
<td>Time One Self-Esteem</td>
<td>-</td>
<td>0.186</td>
</tr>
<tr>
<td>Time Two Self-Esteem</td>
<td>-</td>
<td>0.544</td>
</tr>
<tr>
<td>Time Zero Sense of Power</td>
<td>-</td>
<td>0.061</td>
</tr>
<tr>
<td>Time One Sense of Power</td>
<td>-</td>
<td>0.691</td>
</tr>
<tr>
<td>Time Two Sense of Power</td>
<td>-</td>
<td>1.066</td>
</tr>
<tr>
<td>Time Zero Experienced</td>
<td>0.180</td>
<td>0.608</td>
</tr>
<tr>
<td>Discrimination</td>
<td>-</td>
<td>0.018</td>
</tr>
<tr>
<td>Time One Experienced</td>
<td>-</td>
<td>0.334</td>
</tr>
<tr>
<td>Discrimination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix K: Subject Group Themes

Group Members’ Themes
Significant Others’ Themes

- Raised activity levels
- Independence
- Asserting self-confidence
- Connection with host organisation
- Social inclusion
- Calm
- Mood improvement
- Self-care
- Difficulties establishing source of changes
- Self-confidence
- Strengthened relationships
- Reduces carer responsibility
- Difficulty addressing topic at home
- Self-awareness
- Understanding of managing situations
Facilitators’ Themes
Appendix L: Overall Themes