Development of a tool to assess how people with intellectual disabilities respond to stigma

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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.

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Overview

This thesis describes the creation of a new tool which aims to further our understanding of how people with intellectual disabilities respond to stigma. It has been proposed that responses to stigma can mediate the impact it has on a person's sense of self and therefore is an important phenomenon to investigate for this highly stigmatized group of people.

Part one is a conceptual introduction which examines the existing literature on stigma theories and models, the impact of receiving stigma, and subsequent responses enacted by the stigmatized. It also examines the picture-story task, a method used in other areas of intellectual disability research to investigate social-cognitive concepts with this population. There is a dearth of stigma theory directly relating to intellectual disability compared with other stigmatized groups, and much of the literature covered relates to mental health stigma. However, there is growing evidence that these theories are also applicable to the intellectual disability population.

Part two is an empirical study which documents the creation of the Responding to Intellectual Disability Stigma tool, including consultation with experts by experience. It also examines the new tool's acceptability and feasibility, as well as initial psychometric properties by comparing scores with measures of wellbeing and self-esteem. Results indicate that the tool has good acceptability and feasibility, is effective in eliciting responses to hypothetical stigmatizing scenarios, and initial correlations with self-esteem are promising. This exploratory study therefore indicates that the new tool warrants further investigation and validation, with a larger and broader sample to further refine the noted limitations.

Part three is a critical appraisal of the empirical study. It covers the impact of COVID-19 as well as ethical considerations and challenges in designing the study. It also includes further consideration of the findings, limitations, and implications for further research. Personal reflections are included throughout.

Impact Statement

The main impact of this study is the creation of a tool which is able to capture a range of responses experienced internally and enacted behaviourally by people with intellectual disabilities in the face of stigma. This is the first tool which has attempted to directly measure the resistance and internalisation of public intellectual disability stigma, which has important implications for further research in this field. It has been previously evidenced that receiving stigma can result in mental health difficulties in some people with intellectual disabilities as a result of the internalisation of publicly held views, and so understanding this process is of high importance when considering wellbeing. The new tool is of particular relevance for interventions designed to improve stigma resistance as it has the potential to be used to measure change over time as well as differences between intervention groups.

Although initially designed as a research tool, the new measure has implications for clinical practice. Every person with an intellectual disability will have experienced varying degrees of stigma throughout their lives and understanding how much of an effect it has had on individuals' accessing metal health services could be useful in developing interventions and care plans.

This study has shown the importance of including people with intellectual disabilities in the creation and development of research which is conducted into their group. Experts by experience were consulted at several stages as well as anecdotal feedback taken from each participant regarding their experience of the study. However, this could be taken further in future studies by having a co-researcher with an intellectual disability.

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Part 1: Conceptual Introduction

A review of the psychological impact of stigma and the responses enacted by those subjected to it with a focus on intellectual disability stigma

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Abstract

Aims

This paper aims to review theories of stigma and the subsequent impact on individuals facing stigmatized attitudes and discrimination by broader society. It brings a specific focus to intellectual disability stigma, as well as methods of assessing complex concepts in this population, in order to inform the development of the new Responding to Intellectual Disability Stigma (RIDS) Tool.

Methods

Web of Science was used to search the literature for relevant papers related to both stigma theory and methods used to create measurements relevant to the intellectual disability population. Reference lists were also searched to identify further relevant literature, as were previous systematic reviews.

Results

A range of responses were reported to be enacted by members of marginalised groups when faced with stigma. The method of using picture-story tasks with people with intellectual disabilities has been found to be an effective method of eliciting thoughts, affect, and behaviour in hypothetical social interactions.

Conclusions

Stigma can elicit a range of responses from members of marginalised groups and the way in which people respond can differentially affect their sense of self. Therefore, the picture-story task will be used to assess how people with intellectual disabilities respond to stigma in the newly developed RIDS tool.

Introduction

The key aim of this project was to develop a new tool to measure responses to intellectual disability stigma, using content analysis to categorise the responses of adults with intellectual disabilities to hypothetical stigmatizing vignettes. Research has shown that belonging to a stigmatized group can negatively impact mental health, wellbeing, and self-esteem (Ali et al., 2015). However, this is not true for all members of stigmatized groups. It has been hypothesised that the way in which an individual responds to discriminatory attitudes and actions can mediate the impact such attitudes have on their sense of self (Thoits, 2011), with resistance to stigma shown to protect against stigmatizing experiences (Firmin et al., 2016; Griffiths et al., 2015; Sibitz et al., 2009).

The stigma people with intellectual disabilities often face has been shown to lead to multiple negative outcomes, including contributing to a variety of physical and mental health difficulties (Ditchman et al., 2013; Jahoda et al., 2010; Richard & Donkin, 2018). Currently, there is no measure or method which has been designed to assess how people with intellectual disabilities respond to stigma and measures designed for other stigmatized groups are not appropriate. Therefore, this project set out to develop a new tool, the Responding to Intellectual Disability Stigma (RIDS), investigate the acceptability and feasibility of administering it remotely in the context of the COVID-19 pandemic, and collect preliminary data on its psychometric properties. It was hoped that if found to be acceptable and feasible, the RIDS could be used in clinical and research settings to assess responses to stigma, as well as change over time in the context of receiving interventions designed to improve stigma resistance. The following literature review synthesises prominent theories of stigma and explores how belonging to a stigmatized group can impact mental health and wellbeing, with a focus on intellectual disability. It also reviews current measures of intellectual disability stigma and considers methodologies relevant to investigating complex concepts in individuals with intellectual disabilities.

Stigma

Originally conceptualised by the ancient Greeks, the term ‘stigma’ referred to bodily signs burnt onto the skin of individuals, to depict that the signifier possessed an undesirable moral status. Those with stigmata were considered to be blemished and subsequently avoided by those without. The concept of stigma became prominent in the social sciences after Goffman’s (1963) seminal book in which he defined the process of stigma as the reaction of others spoiling normal identity. As such, stigma refers to an attribute which is considered deeply discrediting and which often elicits negative attitudes from those who do not possess said attribute. However, Goffman (1963) also stated that it is within relationships that stigmatization occurs, as opposed to stigma being a decontextualized concept. The stigmatized person is seen as not quite human and becomes the target of discrimination which reduces their life chances.

The importance of social processes and power differentials continues to be highlighted in recent literature, where it is widely reported that negative attitudes alone do not explain the experience of stigma (Werner et al., 2012). Link and Phelan (2001) sought to encompass the many previous definitions of stigma, which they defined as the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination within a situation of unequal power. They stressed the importance that this conceptualisation moved beyond merely the cognitive component of stigma to include discriminative action and negative consequences for those labelled as possessing a stigmatized attribute. Others have defined such negative discriminatory actions as enacted stigma (Griffiths et al., 2015).

The Psychological Impact of Stigma

The psychological ‘violence’ of stigma often results in a reduction of all the possible ways of being for a stigmatized person, who may be unable to define themselves as they see themselves (Howarth, 2006). Stigmatization has been described as a painful situation in which an individual is aware of their perceived inferiority, thus creating in some a chronic feeling of insecurity, anxiety, and jealously, and can induce feelings of shame related to their perceived difference (Goffman, 1963). Furthermore, stigma is intimately tied to the reproduction of social difference and social exclusion (Parker & Aggleton, 2003) and, as positive self-esteem is created via a sense of control over one’s environment, such social exclusion can create a reduced sense of control and subsequent low self-esteem (Branscombe et al., 1999). To cope with the negative expectations and discrimination marginalised groups may come to expect, devalued group members can withdraw from social interactions and attempt to keep their devalued label a secret (Link et al., 1989). In addition, some stigmatized individuals can go to extreme lengths to remove or correct the attribute they possess, for example through surgery, and may even break with reality in order to cope with the negative effects of stigmatization (Goffman, 1963).

A meta-analysis found that stigma of mental health problems was correlated with increased symptom severity, poorer treatment adherence, reduced self-esteem, reduced hope, and reduced empowerment (Livingston & Boyd, 2010). Similarly, intellectual disability stigma has been found to be associated with higher levels of psychological distress as well as reduced quality of life (Ali et al., 2015). As such, individuals labelled as belonging to a marginalised group for a certain shared, devalued attribute must cope with the symptoms of the attribute itself, as well as the effects of the associated stigma (Corrigan & Watson, 2002a).

Theories and Mechanisms of Stigma

Labelling is the first phase identified in Link and Phelan's (2001) stigma definition and accordingly labelling and identity theory have been cited in subsequent literature as essential to understanding how beliefs and actions of the dominant, more powerful group affect a stigmatized individual's sense of self (Marcussen & Asencio, 2010). Three types of stigma have been identified in the literature: public stigma, self-stigma, and affiliate stigma. Public stigma is defined as a widely accepted, devalued position of a group of people who have been labelled negatively due to a shared undesirable attribute. It refers to the stigmatizing attitudes and behaviours that others, the 'stigmatisers', hold and enact towards members of such stigmatized groups. Self-stigma refers to the perception held by a stigmatized individual that they are socially unacceptable and often results in a reduction of self-worth (Vogel et al., 2007). Finally, affiliate stigma refers to the devaluation and discrimination experienced by those associated with an individual labelled as owning an undesirable attribute (Mitter et al., 2019).

The 'looking glass' hypothesis of the approach to self states that those members of a devalued group who recognise the prejudice received from the dominant group are more likely to internalise this prejudice, resulting in low self-esteem (Branscombe et al., 1999). In their investigation of mental health stigma and its impact on accessing services, Vogel et al. (2013) concluded that experiencing public stigma does indeed precede the development of self-stigma, supporting the idea that it is the internalisation of stigma associated with mental health problems which results in prejudices and stereotypes subsequently transforming into negative beliefs about oneself (Lucksted & Drapalski, 2015). Furthermore, modified labelling theorists state that the poor self-esteem and wellbeing which can result from receiving a devalued label occurs through a process of anticipated discrimination (Link et al., 1989). As such, the expected devaluation and discrimination that a person with a stigmatized label experiences, enables public stigma to be applied to the self. This finding was replicated by Quinn and Chaudoir

(2009) who concluded that the centrality of one’s stigmatized identity and its salience were the two internal mechanisms that mediated the internalisation of a stigmatized label.

Stereotypes allow human beings to categorise information and can have both positive and negative outcomes. When considering negative outcomes, stereotypes have been described as broader society identifying and defining characterisations of people with certain conditions (Corrigan & Rao, 2012). If a member of society agrees with this characterisation, it is connected with a negative emotional reaction which is defined as prejudice. Therefore, prejudice takes place when negative societal attitudes regarding a group of people are endorsed by an individual, eliciting emotions such as fear, regarding the stigmatized group (Werner et al., 2012). Prejudice has also been described as capable of harming both physical and mental health (Branscombe et al., 1999) via a process in which the negative emotions of prejudice are acted upon, resulting in a negative behavioural response: defined as discrimination (Corrigan & Rao, 2012). The effect of discrimination is therefore harm caused to members of the devalued group (Crocker et al., 1998); for example, experiencing prejudicial feelings about a group of people deemed to possess an undesirable trait can result in social distancing. This process is paralleled in self-stigma, in which a person endorses a negative stereotype of themselves and may engage in self-discriminatory actions, such as self-isolation (Corrigan & Rao, 2012). Following self-stigmatization, an individual often experiences further negative emotional reactions, poor self-esteem, and poor self-efficacy (Watson et al., 2007).

Importantly, both public and self-stigma involve much more than the cognitive processes of labelling and stereotyping, whether these are directed at the other or the self (Link & Phelan, 2001; Quinn & Chaudoir, 2009; Werner et al., 2011). Therefore, in addition to understanding these internal processes, it is essential to understand the broader society in which prejudice and discrimination occur. Thus, understanding stigma requires an understanding of power constructs to investigate who the dominant groups are that determine whether or not a certain attribute is labelled as negative, and its carriers rejected and discriminated against (Howarth, 2006). In her conceptualisation of racial stigma, Howarth (2006) argued that stigma is political, using social representations theory (SRT; Moscovici, 1984) to note that stigmatized representations filter into and construct the institutionalised practices of differentiation, division, and discrimination that certain minority groups face. As such, if action is to be taken to counter stigma, it must take place at both the collective, public level as well as at the individual level (Jahoda & Markova, 2004).

Variable Outcomes to Stigma

Although there is a wealth of research depicting and evidencing the negative impact on those labelled as undesirable and devalued, not all those who face public stigma go on to develop self-stigma (Branscombe et al., 1999; Marcussen & Asencio, 2010). Corrigan and Watson (2002a) described an alternative, seemingly paradoxical reaction in which public stigma results in energising and righteous anger, leading to empowerment, as opposed to self-devaluation. Some labelled with stigma may also display a third response and experience neither loss of self-esteem nor righteous anger, and seemingly appear indifferent to the public label placed upon them (Corrigan & Watson, 2002b). In this model, the authors identified an appraisal process in which an individual determines whether or not the discrimination they receive is legitimate. If they deem it legitimate, self-esteem is negatively affected. If not, self-esteem remains intact, and a second cognitive appraisal is made regarding group identification. If an individual identifies with the discriminated group, then the response is righteous anger. If not, the response will usually be one of indifference.

Developing this model further, the researchers argued that perceived discrimination does not measure self-stigma directly, but rather measures stigma awareness (Watson et al., 2007). The authors proposed that perceived legitimacy and group identification lead to stereotype awareness, followed by stereotype agreement, followed by self-concurrence, before self-esteem and self-efficacy may be negatively affected. Therefore, in this cognitive understanding of self-stigma, individual differences in self-stigmatizing beliefs are explained by varying degrees of self-concurrence (Young et al., 2020).

Similar effects have been shown in racial stigma models, in which those who recognise the powerful group's view of their minority group membership are more likely to internalise negative evaluations, resulting in low self-esteem (Branscombe et al., 1999). However, this is not true for all members of the racially discriminated and it has been argued that attributing negative outcomes to prejudice can be protective among devalued groups (Crocker & Major, 1989).

Stigma Resistance

Theorising the phenomenon of those who do and do not internalise stigma in more detail, Thoits (2011) sought to explain why the correlation between public devaluation and low self-esteem was found to be only moderate in the majority of stigma research. She concluded that the mechanism of stigma resistance protects the self against external discrimination and described resistance as opposition to a harmful force or influence. Thoits' proposal, based on modified labelling theory, states that stereotypes are perceived by those within a devalued group as threatening, which can result in secrecy, withdrawal, or education. To respond to stigma, an individual must first be aware that a certain label applies to them, understand that the label could become a public identity, and have knowledge of the cultural meanings of the label. If these three conditions are met, Thoits (2011) identified five response categories beyond being unaware of or denying the label, including self-stigmatization, deflection, avoidance, self-restoration, and challenging. She described deflection and challenging as intentional forms of resistance; challenging pushes back against the harmful influence with force of its own, while deflecting blocks the harmful force by hardening the self. In line with this theory and findings, Howarth (2006) writes that stigmatized groups can become active agents of resistance, rather than being reduced to object, passive victims, while Firmin et al. (2017) concluded that resistance is an active, ongoing process, as opposed to a final state of absent self-stigma.

Stigma resistance has since been described as the capacity to counteract or remain unaffected by stigma (Griffiths et al., 2015) as well as the ability to hold a positive illness identity using one's own skills, knowledge, and experience (Firmin et al., 2017). In addition, resistance has been shown to be positively correlated with self-esteem, empowerment, and quality of life (Sibitz et al., 2009), as well as with social functioning and problem-centred coping (O'Conner et al., 2018). Crocker and Quinn (1998) reported that people engage in a wide variety of strategies to maintain, protect, and enhance their self-esteem and activities such as self-advocacy have been identified as allowing stigmatized group members to develop a more positive self-concept (Anderson & Bigby, 2015). Related to self-advocacy, Branscombe et al. (1999) proposed that identifying with a minority group can enhance psychological wellbeing, as well as damage it. In a meta-analysis investigating stigma resistance among people affected by mental health problems, Firmin et al. (2016) found a large, negative effect size between stigma resistance and self-stigma. In their conceptual model of stigma resistance, these authors concluded that resistance could occur at the personal, peer, and public level. They also identified several key factors of the resistance process, including: a sense of identity distinct from mental health problems, the metacognitive capacity to differentiate the stigmatizing beliefs of others from one's own identity, and finally, a sense of empowerment to feel capable of resisting stigma.

Despite the multiple positive effects of stigma resistance, it is important to note that damage to self-esteem can occur in the absence of stigma internalisation (Thoits, 2011).

Members of a devalued group must still manage the attitudes and discriminatory actions of others, even when these are not internalised.

Intellectual Disability Stigma

The intellectual disability population, who are one of the most highly stigmatized groups (Finlay & Lyons, 2000), have received a comparatively small amount of attention in the world of stigma research (Werner et al., 2012). By contrast, stigma associated with mental health problems and HIV/AIDS has received the most attention and the literature covered in this review mostly draws on writings from the mental health field. Thoits (2011) suggested that her theory of stigma resistance, while based on research in the mental health field, could be applied to stigma more broadly. Its potential fit for the intellectual disability field is supported by the finding that parents of children with intellectual disabilities enacted deflection and challenging strategies in order to resist public stigma (Manago et al., 2017). By using certain disability discourses, they were able to resist the prejudiced views of others as well as directly challenge them. In line with this, Ditchman et al. (2013) argued that mental health related stigma models and conceptualisations are broadly applicable to people with intellectual disabilities, both for understanding and challenging the stigma this group of people face.

Individuals with intellectual disabilities face realistic hardships in their everyday lives, as well as multiple sources of adversity and inequality, and are more likely than people without intellectual disabilities to experience mental health difficulties. Thus, a distinction is required to be made between people’s actual impairments and the social barriers, stigmatizing attitudes, and discrimination they face, which contribute to their increased vulnerability (Jahoda & Markova, 2004). Intellectual disability stigma appears to be positively correlated with psychological distress, negatively correlated with quality of life, and can take the form of abuse, discrimination, and denial of everyday opportunities (Ali et al., 2015). Due to a lack of support, people with intellectual disabilities are often merely physically present in their communities, rather than socially included (Anderson & Bigby, 2015) and can experience stigma via their interactions with others in their community, which is often an emotionally painful experience (Beart et al., 2005).

Stigmatizing beliefs and behaviours regarding people with intellectual disabilities are pervasive and harmful and have even been identified in their carers (Pelleboer-Gunnink et al., 2019), as well as in UK law (Fiala-Butora & Stein, 2016). Scheerenberger (1983) reported that pity and fear underpin intellectual disability stigma and different forms of discrimination have been associated with these two opposing publicly held views; that individuals are childlike and need protecting, and that they are predatory and dangerous and should be avoided (Jahoda et al., 2010). In a systematic review of research into public attitudes regarding intellectual disability, Scior (2011) reported that this group were consistently identified as the least desirable of all disability groups as partners for social interactions. In addition, negative public attitudes and behaviours were found to be modified by the perceived severity of a person's disability, as well as degree of previous exposure to people with intellectual disabilities, with more perceived severity and less exposure predicting more negative attitudes.

Perceived incapability across all areas of life appears central to negative stereotypes held about this group by the public and interventions directed at education regarding capability have seen some improvements (Scior, 2011). Interestingly, the review found that social desirability was not directly correlated with negative attitudes and may be better explained by the mediating factor of anxiety and discomfort. In a further study of public attitudes, Scior et al. (2013) found that, despite the rights of people with intellectual disabilities being generally well supported, at least in self-report measures, social distance remained high and tended to be increased among those who viewed intellectual disability symptoms as attributable to character flaws. These findings were replicated in a further study which also concluded that support for rights and acceptance were lower for the intellectually disabled than physically disabled population, as well as a higher number of stereotypes and greater social distance (Werner, 2015).

Labelling Theory and Intellectual Disabilities

The label of intellectual disability has been described as a ‘master status’ (Hughes, 1945), which is so powerful that it can override all other aspects of a person’s identity, including race, gender, sexuality, and religion as well as overshadow signs of mental health difficulties (Beart et al., 2005). The social identity of persons with intellectual disabilities can be devalued and depersonalised into stereotypic caricatures (Werner et al., 2012), and awareness of social stigma has been found to be significantly related to low self-esteem and self-comparison in this population (Paterson et al., 2012). Many individuals are aware of the negative connotations of the label they have been given and can identify the bullying, rejection, and limitations placed on them due to being labelled as intellectually disabled, in addition to the stigma associated with specific activities, such as attending day services (Logeswaran et al., 2019; Sheehan & Ali, 2016). In response, people with intellectual disabilities may then enact a number of psychological and behavioural responses to distance themselves from such an identity, or deny it altogether (Crabtree et al., 2016; Logeswaran et al., 2019).

Intellectual Disability and Self-Stigma

According to social identity theory, self-evaluation in members of stigmatized groups occurs as a consequence of the views that others hold of them, as well as the ability to make comparisons (Tajfel & Turner, 1979). Mirroring findings from the general population, social comparison has been found to be associated with self-esteem in the intellectual disability population (Dagnan & Sandhu, 1999). It has also been reported as a key process in the internalisation of intellectual disability stigma, in which negative social comparison increases the likelihood of self-stigmatization, while positive social comparison protects against it (Dagnan & Sandhu, 1999; Finlay & Lyons, 2000; Paterson et al., 2012). Awareness of the intellectual disability label, as well as degree of perceived stigma, are negatively correlated with low self-esteem in the self-comparison process (Paterson et al., 2012) and there is evidence that the internalisation mechanism described in the wider stigma literature is also applicable to this group. Dagnan and Waring (2004) found that perceptions of stigma were correlated with self-evaluative cognitive processes and concluded that core negative beliefs about the self were directly related to the experience of feeling different. In addition, Sheehan and Ali (2016) reported that Watson et al.'s (2007) model of self-stigma also applies to the intellectual disability population. They described a process of initial awareness of one's stigmatized status, which can lead to agreement and application of negative stereotypes to oneself, resulting in low self-esteem and self-discriminatory behaviours. In summary, previous studies have therefore evidenced that the social-cognitive conceptualisation of the internalisation of public stigma developed in other stigma fields is also applicable to the intellectual disability field.

Intellectual Disability and Stigma Resistance

There has been little research directly related to how people with intellectual disabilities may resist stigma. However, in an early study, Jahoda et al. (1988) found that the self-concept of people with intellectual disability was created by both self-agency as well as internalisation of the views of others. Therefore, even when aware of their stigmatized status, many people did not accept this negative view of themselves. According to Jahoda et al. (1988) this is achieved by distinguishing their disability from the stigmatized status and rejecting the idea that their disability results in lack of self-worth. In line with this, it has been further found that (in an opposite process to that of social comparison resulting in internalisation) downward social comparison to both in-group and out-group members appears to result in positive self-evaluation in those labelled as intellectually disabled (Finlay & Lyons, 2000). Such strategies of positive self-evaluation have been identified as protective of the self and include comparing to in-group members who are less able and have higher levels of behavioural difficulties, as well as comparing to out-group members with morally negative behaviour, for example, people who steal (Crabtree et al., 2016). Importantly, the fact that people with intellectual disabilities chose to compare themselves on dimensions of ability and behaviour indicates that they were aware these attributes are used by others to evaluate them negatively, even when not internalised. This process has also been described as 'internalised ableism' (Spassiani & Friedman, 2014).

Jahoda and Markova (2004) reported a similar finding with regard to protective strategies against stigma. They reported a 'tension' between identification with peers in their oppressed group, against the need to maintain superiority over these peers, in the downward social comparison process. Again, this was in relation to capability and how it is perceived by out-group members, while the ability to reject a stigmatized identity was supported by the belief that people with intellectual disabilities follow the same social rules as people without. Downward social comparison has been replicated in a number of further studies and has been associated with high self-esteem (Monteleone & Forrester-Jones, 2016). These findings support Thoits' (2011) theory that awareness of consequences of certain labels is a prerequisite to resistant responses and can be viewed as a deflecting strategy against stigma. However, despite protecting self-worth, downward social comparison also presents a dilemma in that by distancing oneself from the group, an individual risks rejection or exclusion from both the minority group as well as broader society. They are also prevented from experiencing the protective righteous anger and collective activism that comes from belonging to a marginalised group.

In a review of identity construction in people with intellectual disabilities, it was found that whilst many were aware of the intellectual disability label, most did not consider it important and some dismissed it altogether, when defining their own sense of identity (Logeswaran et al., 2019). However, despite not viewing this label as a central part of their identity, many reported feelings of shame, embarrassment, and dejection as well as anger, frustration, and powerlessness. The review concluded that such emotions led to a variety of responses, including seeking to create a new identity, resisting any inference of having an intellectual disability, rarely using the label in reference to themselves, or rejecting it completely. The authors cite identity process theory (Jaspal & Breakwell, 2014) as a possible explanation for these responses, as the intellectual disability label can be viewed as a threatened identity which results in a variety of coping mechanisms to distance oneself (Logeswaran et al., 2019). Dorozenko et al. (2015) reported a similar finding, in which members with intellectual disability did not use this label to identify themselves but were aware of the societal views which dehumanised them and constructed them as different, incompetent, and burdensome.

These reported mechanisms are in line with the key processes of stigma resistance (i.e. a distinct sense of identity, the capacity to differentiate the stigmatizing beliefs of others from oneself, and a sense of empowerment) proposed by Firmin et al. (2017), who described stigma resistance as an ongoing process. This was also identified in the intellectual disability literature, where individuals described in a case study were reported as “actively trying to make sense of the world and establish their own identities within it” when coping with stigma (Jahoda et al., 2010, p. 530). One means of collective resistance, self-advocacy, is gathering growing support as a route to the development of a positive sense of identity by rejecting stereotyped labels, making choices, and exercising civil rights (Spassiani & Friedman, 2014).

Stigma Measurement

As detailed above, there is a wealth of evidence that the internalisation of public stigma often results in self-stigmatization via a cognitive process of awareness, agreement, and application to the self, resulting in low self-esteem and self-discriminatory behaviours. What has also been shown in the literature is that resisting stigma can protect the self from negative public perceptions and the resultant negative impact on wellbeing. Stigma resistance can also increase one's sense of empowerment (Campbell & Deacon, 2006). In order to assess the effect of stigma on an individual, tools are required to measure how the person affected responds to the stigma they face. In the mental health field, such measures have been developed to assess both self-stigma and stigma resistance. Fox et al. (2018) found that since a previous review in 2004, 957 articles contained at least one stigma measure. They reviewed 140 in detail, only including those which had been cited in an additional text and included psychometric data. Of these, 28% were from the perspective of the stigmatized and the remaining 78% were developed from the perspective of the stigmatiser.

This degree of stigma investigation has not been evident in the intellectual disability field. In their review, Werner et al. (2012) identified only five scales designed to measure stigma directly with people with intellectual disabilities and further concluded that these scales aimed to measure perception of stigma alone, as opposed to its internalisation or resistance. As such, the authors concluded that there was a need for scale development which applies the self-stigma framework to the intellectual disability field. A subsequent literature search was conducted as part the current literature review, using the same search criteria described by Werner et al. (2012), from the date of their publication to the present. The search criteria used were intellectual disability, developmental disability, learning disability, cognitive disability, and mental retardation, along with questionnaire and scale, and stigma. This search identified 134 papers, whose titles and abstracts were searched for evidence of the development of new self-stigma measures for people with intellectual disabilities. Two papers were identified which appeared relevant, Geiger and Brewster (2018), and Daley and Rappolt-Schlichtmann (2018). However, examination of the full text revealed that Geiger and Brewster (2018), despite their measure being called the 'Learning Disability/Difficulty Perceived Discrimination Scale' had excluded participants with an intellectual disability, instead focussing on specific learning difficulties, such as dyslexia. As such, the search concluded that one further measure of intellectual disability self-stigma had been developed since the Werner et al. (2012) review, and the six measures in existence are reviewed below in chronological order of publication.

Intellectual Disability Self-Stigma Measures

The Stigma Scale (Szivos, 1991)

The Stigma Scale is a ten-item measure, answered on a five-point Likert scale of agreement to each item statement and was designed for use with adolescents with intellectual disabilities in a study of how they compare themselves to non-disabled siblings. Items were created from various pre-existing stigma measures, as well as discussion with adolescents with intellectual disabilities. Cronbach alpha for the scale was high (.81), with good item correlations (.34 to .62). In the same study, a new measure of social comparison was created, using 12 positive and 12 negative items covering the factors of: power over and significance towards other people, adherence to normative virtues and values, and competence. These two measures were combined when the results showed how closely social comparison and stigma were correlated. The combined stigma/ social comparison measure had a high internal consistency (Cronbach's alpha of .90) and further analysis identified five factors: positive self, social competence, being different, anxiety, and work competence.

The Social Comparison Scale (Dagnan & Sandhu, 1999)

The Social Comparison Scale is a six item, three factor scale adapted from the original which was designed for the non-disabled population (Allen & Gilbert, 1995; Gilbert & Allen, 1994). It asks participants to complete incomplete sentences, to assess their comparison to self and others on factors of rank and achievement, social attractiveness, and belonging. To adapt for the intellectual disability population, answers are recorded on a visual analogue scale in the form of a 12.5 cm line divided into five segments, as opposed to the original 10-point ranking system. Wording is also simplified, and each item presented in large print on a single page. Despite factor analysis initially indicating a two-factor structure of the adapted version, further analysis showed that the original three factor structure was also applicable to the intellectual disability understanding of social comparison.

Experience of Stigma Checklist (Cooney et al., 2006)

The Experience of Stigma Checklist is a 13-item measure including eight weighted items, interspersed with five additional items relating to non-stigma experiences. Participants answer in terms of frequency of experience of each item on a five-point Likert scale regarding experiences with key figures in their lives, along with examples to justify their response. The authors report moderate Cronbach's alpha scores (.48 to .63) and good inter-rater reliability in terms of agreeing whether the experiences reported could be labelled as stigmatizing or not. The authors did not report how individual items were produced and whether this was done in collaboration with people with intellectual disabilities.

Tool to Measure Self-Perceived Stigma (Ali et al., 2008)

This instrument is a ten-item measure of statements related to stigma, answered in a yes/ no format. Items were created from analysis of conversations about stigma in focus groups with people with intellectual disabilities, professionals, and carers. Initial items were piloted with a group of people with intellectual disabilities who were asked to comment on applicability of items and understandability of wording and illustrations. Factor analysis resulted in the final ten items and indicated a two-factor model: 1. perceived discrimination and 2. reactions to discrimination, which accounted for 60% of the variance. Overall Cronbach alpha was .84, .72 for factor 1, and .69 for factor 2 while test-retest was acceptable with kappa ranging from .41 to .71.

Attitudes to Disability Scale (ADS; Power et al., 2010)

The ADS is a 16-item measure, comprising of four subscales, which can also be combined into one, overall score of attitudes to disability. The four subscales are: inclusion and exclusion, discrimination, positive gains, and hopes and prospects. The ADS was developed in consultation with people with intellectual and physical disabilities (PD) and their families and can be used separately for either group. The ADS includes a ‘personal’ version to be used with people with disabilities, and another ‘general’ version to be used by the public. As such, four versions of the ADS exist: ID personal, ID general, PD personal, PD general. The authors reported good Cronbach alpha for both disability populations (.76 to .80), except for the four items which make up the positive subscale. Factor analysis showed a better fit for both personal versions compared with the general population versions.

Stigma Consciousness Questionnaire–Learning Disabilities (SCQ-LD; Daley and Rappolt-Schlichtmann, 2018)

The SCQ-LD is a 12-item measure, answered on a four-point Likert scale from ‘strongly disagree’ to ‘strongly agree’ to statement items. This measure was adapted for the adolescent learning disability population, based on the original which was designed to assess stigma consciousness among women (SCQ: Pinel, 1999). The learning disability adaptations were achieved via progressive refinement and testing, initially with an advisory board of researchers, followed by two pilot groups of adolescents. The pilot groups included semi-structured qualitative interviews to discuss readability, understanding, accessibility, and usability. Psychometric analysis of an initial 15 items resulted in the removal of three, and

Cronbach's alpha of the final 12 items was found to be excellent at two time points (.82 and .84). Test-retest reliability was found to be stable over a time period of four to six weeks with a correlation of .80. The SCQ-LD was also found to be moderately positively correlated with expected related measures, indicating acceptable construct validity.

These stigma measures cover a range of factors relating to frequency of stigmatizing experiences, social comparison, and the perception of attitudes towards people with intellectual disabilities. All six report at least good scores on tests of reliability and validity. However, what appears to be missing is a measure to assess how people with intellectual disabilities respond to stigma. Considering the social-cognitive conceptualisations described above, individual responses to public stigma can be used to understand how people with learning disabilities manage the negative attitudes and behaviour of others and whether or not they are able to resist the public stigma they are faced with. This is particularly relevant when considering the processes of agreement and application to the self, as well as self-discriminatory behaviour as the mechanisms associated with internalisation.

Methods

Assessing Complex Concepts in People with Intellectual Disabilities

Intellectual disability is defined by significant cognitive and functional deficits and is often associated with difficulties in communication (Boat & Wu, 2015). This poses a difficulty when conducting assessments and verbal interviews, as understanding complex issues, such as stigma, as well as articulating emotional and cognitive responses may be challenging for some. As such, there is a need for the development of creative methods of assessing complex concepts in people with intellectual disabilities in order for their voices to be heard (Pert et al., 1999). In the literature investigating aggression in the intellectual disability population, which is also theorised to be a social-cognitive process, several studies have reported on the use and effectiveness of using picture-story tasks. Such tasks support individuals with intellectual disabilities to understand what is being asked of them through a scaffolding process and this method has been found to elicit appropriate responses regarding the concept being investigated (Pert et al., 1999).

Building on earlier work regarding cognitive biases related to aggression in children by Dodge and Frame (1982), and intellectual disability by Fuchs and Benson (1995), Pert et al. (1999) reported that their picture-story task was a successful method of assessing attributional intent in people with intellectual disabilities. Picture-story tasks involve presenting hypothetical vignettes verbally, alongside photographs in a storyboard format, from a first-person perspective to help the individual immerse and imagine themselves in the situation presented (Esdale et al., 2015). Interviewees are then asked a series of questions regarding their emotional, cognitive, and behavioural responses to the scenarios. Using this approach, participants have been found to be able to consistently answer from both self-referent and other-referent perspectives to a variety of scenarios related to aggressive behaviour (Pert et al., 1999). This indicates that the task was understood, and that the method was effective in allowing participants to effectively role-take and express their cognitive and emotional reactions when interpreting attributional intent of the other. This study reported almost-perfect inter-rater reliability when coding such responses, which further evidences this method as suitable and effective for the purpose of eliciting and categorising the responses of people with intellectual disabilities in social interactions.

The efficacy of picture-story tasks has been replicated in a number of further studies designed to assess complex cognitive processes in people with intellectual disabilities. The Praise and Criticism Task (PACT), developed by Esdale et al. (2015), used ten hypothetical scenarios, each with three photographs, to ascertain responses to criticism and praise. The PACT was reported to effectively elicit emotional and cognitive responses from participants.

The authors also reported high inter-rater reliability for content analysis of the themes identified from participant responses. Similar results were reported in the development of the Beliefs About Responses to Threat Task (BARTT; Kirk et al., 2008) which was designed to assess outcome expectancy, as well as beliefs about aggressive and submissive responses to threat, in people with intellectual disabilities. Good inter-rater reliability was reported for content analysis of open-ended questions and the BARTT was reported to distinguish responses between aggressive and non-aggressive individuals. A further novel assessment using the picture-story method was reported as effective in eliciting expected outcomes and emotional responses of people with intellectual disabilities when asked about conflict and aggressive strategies (Pert & Jahoda, 2008). The Social Goals and Strategies for Conflict (SGASC) assessment again used coded responses to hypothetical vignettes. The authors reported good inter-rater reliability and concluded that the SGASC could reliably distinguish between the responses of those participants in the aggressive and non-aggressive groups (Pert & Jahoda, 2008).

Consultation with people with intellectual disabilities is essential when developing picture-story task vignettes, to ensure they are relevant and understood by individuals from this population (Jahoda et al., 2006). Another important aspect reported in the previous literature when using such tasks, is the impact of social desirability on answers given by participants (Pert et al., 1999). This was mitigated in previous studies by reassuring participants that there were no right or wrong answers, emphasising that their view was most important, and that responses would be kept confidential. In addition, to reduce the chance of a negative response set, previous studies included positive and neutral hypothetical social interactions (Pert & Jahoda, 2008). Following picture-story tasks, participants have been asked about a happy event that has occurred recently and reminded that the stories were made up, to prevent them from ruminating on negative social experiences (Kirk et al., 2008).

The picture-story task has therefore been shown as a reliable method to elicit the emotional, cognitive, and behavioural responses of individuals with intellectual disabilities during interpersonal situations, as well as their intent behind such responses. Although previously used in experiments of aggression, this method is also applicable to stigma. Experiencing stigma is intimately tied to aggressive behaviour, as experiencing discriminatory life events leads to the development of negative beliefs and attitudes, which influence the interpretation of current events as threatening, leading to aggressive responses (Pert et al., 1999). In addition, this method accesses emotions, thoughts, actions, and intent in response to interpersonal situations, which is essential to understanding how people with intellectual disabilities respond to potentially stigmatizing situations.

Picture-Story Task Development

It is well documented that people with intellectual disabilities are subject to stigma. However, in developing the RIDS tool, knowledge of the context and content of stigmatizing interactions was crucial. Therefore, the literature was searched for examples of stigmatizing situations faced by people with intellectual disabilities, to be included in the new measure.

Jahoda et al. (2010) reported that people with intellectual disabilities can be viewed both as incapable and over-protected, as well as dangerous and avoided, and these opposing views have been described as a tension between fear and concern (Ditchman et al., 2016). When investigating stigmatizing experiences of adolescents with intellectual disabilities, Cooney et al. (2006) found that they reported being ridiculed, ignored, the targets of violence and restrictions, given unwanted extra help, or conversely not given enough help, and others getting angry with their mistakes. In line with these findings, Dovidio et al. (2000) reported that people with intellectual disabilities are systematically avoided, derided, and marginalised. In their review, Logeswaran et al. (2019) found that people with intellectual disabilities had experienced being laughed at, insulted, treated differently, ignored, and rejected. In research co-conducted by a researcher with an intellectual disability, Corr McEvoy and Keenan (2014) found via focus groups that participants were ‘slagged’ (called unkind names), bullied, refused jobs, treated like children, treated as incapable, stared at, and ignored. Participants also reported being short-changed, rushed, or not served in pubs and shops, and verbally abused by strangers on public transport. They further reported not being allowed to make their own decisions, especially when it came to relationships. People with intellectual disabilities are also more likely to be the victims of abuse than non-disabled peers and this can take the form of physical injury, sexual assault, emotional trauma, financial abuse, medication mismanagement, and refusal to provide necessary personal assistance by others in the community (Ditchman et al., 2016). In summary, the negative experiences reported in the literature, arising from the stigmatized status in society of people with intellectual disabilities, can be broadly categorised as verbal and physical abuse, social exclusion, avoidance/ social distance, infantilisation, denial of everyday opportunities, denial of autonomy, and denial of capability.

Expert by Experience Consultation

In regard to the development of the RIDS, Jahoda et al. (2010) reported that the creation of a picture-story task requires consultation with people with intellectual disabilities. ‘Nothing about us without us’ is a term which has been adopted by multiple marginalised groups as a slogan for communicating the need for research and policies regarding oppressed groups to be conducted for, with, and by them, rather than to, without, and on them. First termed in literature analysing disability oppression and empowerment, one of the main arguments was that “the scant attempts to theorize the conditions of everyday life for people with disabilities are either incomplete or fundamentally flawed as a result of the medicalisation/ depoliticization of disability” (Charlton, 2000, p.IV). In his article on the ethics of outsider research in response to Charlton’s book, Bridges (2001) reported four overarching reasons for the need for insider research: only insiders can properly represent the experience of their group, outsiders can produce damaging frameworks, outsiders may exploit the participants they research, and outsider research can disempower insiders. Historically, research on people with intellectual disabilities was done without their consent, and could be harmful and exploitative (Freedman, 2001). Gjertsen (2019) further concluded that although including people with intellectual disabilities in research could make the process more complicated for the researcher, having the first-hand voice of participants adds quality to the data. When people with intellectual disabilities are not included in research, they are kept from experiencing both the direct and indirect benefits of research and their ability to contribute to society is also diminished (McDonald et al., 2016). Therefore, there is growing evidence for the long-overdue fact that the voices of people with intellectual disabilities must be heard, and their views adequately responded to in research regarding their community.

New Measure Validation

Following the social-cognitive models of responses to stigma described above, responses to stigma have so far been indirectly measured in the existing literature via assessments of self-esteem and psychological distress (Ali et al., 2015; Watson et al., 2007). Therefore, the new RIDS tool, which assesses the responses of individuals with intellectual disabilities to a range of stigmatizing everyday encounters and is presented in part 2 of this thesis, will be validated against existing measures of self-esteem and psychological wellbeing.

The Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965) is the most widely used assessment of the self and has been reported in a number of studies to be a reliable and valid measure of global self-worth (Robins et al., 2001), which deserves its popularity and wide-spread use (Gray-Little et al., 1997). Although there have been some who question the effectiveness of the original RSES with participants who have intellectual disabilities due to poor internal reliability (Davis et al., 2009), a later Rasch analysis of the scale's psychometric properties concluded that item fitness and difficulty, rating scale analysis, and reliability outcomes, all indicated that it was an appropriate measure to use with this population when assessing self-esteem (Park & Park, 2019). A number of studies report the efficacy of using the adapted version of the RSES produced by Dagnan and Sandhu (1999) for people with intellectual disabilities (Paterson et al., 2012). The adapted version is based on a later version of the original RSES (Rosenberg, 1982); it has fewer items, simplified language, and includes a visual aid to help represent the Likert structure from one to five, indicating increasing levels of agreement with each item. The adapted version is reported to also have a two-factor structure of positive and negative self-esteem, in-line with the original (Dagnan & Sandhu, 1999).

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007) has been found to be valid, reliable, and responsive to change (Maheswaran et al., 2012). It includes 14 positively worded items to measure psychological wellbeing. It is answered on a five-point Likert scale of agreement to statement items over the previous two weeks and confirmatory factor analysis has shown that it measures a single underlying construct (Tennant et al., 2007). A later Rasch analysis by the same authors found that some items had a bias for gender and age, resulting in an alternative, seven-item version being created (Stewart-Brown et al., 2009). However, the authors commented that there was still use in using the original version in order to explore these biases further in different populations. The WEMWBS has not yet been validated for use with the intellectual disability population, though the items have been reported to have good readability (Daery et al., 2013). However, these authors also concluded, based on a Mokken scaling analysis, that people with lower cognitive ability may find some items difficult to differentiate. Although the authors did not define what constituted 'low cognitive ability' this has implications for use with the intellectual disability population. A subsequent adapted version for people with intellectual disabilities has since been created

(WEMWBS-ID; Scior et al., in preparation) and this version includes simplified language as well as a reduced Likert scale to four points, alongside a visual response aid. This version also includes practice items to check user understanding and the referent time scale has been reduced from the preceding two weeks to one week.

Considering the theoretical and experimental evidence connecting stigma, self-esteem and psychological wellbeing, these measures and their underlying constructs are appropriate and important information to gather alongside the responses to the RIDS.

Cognitive Models and People with Intellectual Disabilities

As described above, the most prominent and evidence-based stigma theories and models include a significant degree of cognitive processing. The label of intellectual disability is characterised by impairments in cognitive ability, as well as difficulties in everyday adaptive functioning, which must be taken into consideration when applying the social-cognitive model of stigma to this population. Similarly, this must also be taken into account when considering the picture-story task and the need for participants to verbalise their emotional and cognitive response to certain stimuli. It has been suggested that the key characteristic elements of alexithymia, defined as the inability to differentiate, describe, and label one’s own emotions (Davies et al., 2015), may also be present in the intellectual disability population (Mellor & Dagnan, 2005). These three elements include difficulty identifying emotions, difficulty describing emotions, and an externally oriented thinking style and limited fantasy life. While these elements have been identified separately, there is not yet evidence that they exist simultaneously in the intellectual disability population (Mellor & Dagnan, 2005). A more recent study did not find evidence in support of the hypothesised association between alexithymia and challenging behaviour in people with intellectual disabilities (Davies et al., 2015), indicating that more research is required regarding this phenomenon in this population.

The literature on ‘readiness’ for cognitive behavioural therapy (CBT) has heavily investigated the ability of people with intellectual disabilities to identify and verbalise thei emotions and cognitions. Using the antecedent-belief-consequence model (Trower et al., 1988), Dagnan and Chadwick (2005) found that people with intellectual disabilities could differentiate emotions, thoughts, and behaviours, concluding that some could easily work with simple cognitive therapy by understanding the link between beliefs and consequences. Of note, the heterogeneity of the intellectual disability group with regard to cognitive capabilities means that these findings are only applicable to the mild to moderately impaired. Dagnan and Chadwick (2005) suggest that the same would not be true for people who have little to no language, and the creation and validation of the RIDS will also be completed with individuals who would be considered to belong to the mild to moderate intellectually disabled group.

Aims

The primary aim of the empirical study was to investigate the acceptability and feasibility of the newly created RIDS tool in assessing responses to intellectual disability stigma using the picture-story method. The second aim was to then categorise the collected responses to intellectual disability stigma and compare these with wellbeing and self-esteem in order to assess initial psychometric properties. An overarching aim of this study was to produce the new measure alongside people with intellectual disabilities, so that it can be of most use to those in this marginalised group in both clinical and research settings.

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Part 2: Empirical Paper

Development of a tool to assess how people with intellectual disabilities respond to stigma

Word Count: 11,818

Abstract

Aims

To develop the Responding to Intellectual Disability Stigma (RIDS) tool in consultation with people with intellectual disabilities. To investigate its feasibility, including online delivery, as well as initial psychometric properties for future development in research and clinical settings.

Methods

The RIDS was created using a picture-story task, a scaffolding technique well-established in intellectual disability research. This is the first time this method has been used to investigate stigma responses. Participants were adults with mild to moderate intellectual disabilities, recruited via social media, third party, and voluntary organisations. The study was completed online via videocall due to restrictions on face-to-face research as a result of the COVID-19 pandemic. Content analysis was used to categorise responses to stigma, and examine the frequency of typologies within the data set, which were preliminarily examined for their association with wellbeing and self-esteem.

Results

Results indicate that the RIDS is a feasible method of eliciting responses to stigma in people with intellectual disabilities. The RIDS was well understood, produced good inter-rater reliability, and identified important relationships between certain emotions, appraisals, behaviours, and motivations within stigmatizing situations. Responses were similar to those described in the wider stigma literature. Results on the RIDS were not associated with measures of wellbeing and self-esteem.

Conclusions

Initial results suggest the RIDS is a promising measure which warrants further investigation and validation. The relationship between stigma, wellbeing, and self-esteem paints a complex picture and existing theoretical frameworks were somewhat supported by this study. The RIDS has the potential to be useful in both clinical and research settings.

Introduction

Defining Stigma

Stigma has been described as an insidious social force (Livingston & Boyd, 2010) and has been defined by Link and Phelan (2011) as the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination within a situation of unequal power which allows stigma to unfold. Considering this definition further, labels considered 'deviant' or undesirable have been found to result in negative consequences for emotional wellbeing and self-esteem, according to modified labelling theory (Marcussen & Asencio, 2010). Stereotypes have been defined as efficient, social knowledge structures that allow people to generate expectations of individuals who belong to a certain group (Corrigan & Watson, 2002b). If a negative social stereotype is endorsed, this is defined as prejudice, which includes the elicitation of an emotion, such as fear or anger. Such prejudice can further result in negative behavioural reactions which are defined as discrimination (Corrigan & Watson, 2002b).

This process has been seen throughout human history, and the term stigma was originally coined back in the time of the ancient Greeks. Stigmata were signs burnt onto the skin of those deemed to possess an undesirable attribute, who were subsequently avoided and rejected by those without. In his seminal paper on stigma and its psychological and social impact on those subjected to it, Goffman (1963) drew particular attention to the negative behaviour of the stigmatiser and defined this relational process as the reaction of others spoiling normal identity. As such, both historical understandings and more recent conceptualisations continue to highlight the importance of understanding stigma in terms of the stereotyped beliefs, prejudiced emotions, and discriminatory behaviours enacted by society, which ultimately limit the lives of the stigmatized. These behaviours or 'enacted stigma' (Griffiths et al., 2015) include members of a marginalised group being laughed at, insulted, treated differently, ignored, and rejected by members of broader society (Logeswaran et al., 2019) as well as coerced, segregated, avoided, subject to hostile behaviours and withholding of help (Corrigan et al., 2003). As a result, many individuals from stigmatized groups develop low self-esteem, poor wellbeing, and mental health difficulties (Ali et al., 2015; Branscomb et al., 1999; Paterson et al., 2011). However, this is not true for all members of stigmatized groups as some may become energised and empowered, or remain indifferent, in the face of stigma (Watson et al., 2007). Consequently, understanding how and why certain individuals are not so affected is attracting increased interest in the stigma field.

Responding to Stigma

Internalisation and Self-Stigma

Across the range of attributes deemed as undesirable, including disease, race, occupation, sexuality, mental health, and intellectual disabilities there is evidence that being subject to stigma can have a substantial negative impact on an individuals' wellbeing and quality of life (Campbell & Deacon, 2006). In understanding how the attitudes and behaviours of wider society can affect the self, it is important to differentiate between the three types of stigma which have been identified in the literature: public stigma, self-stigma, and affiliate stigma. Public stigma is the most thoroughly investigated and refers to the attitudes and discriminatory actions directed at a group by wider society (Corrigan & Rao, 2012). Self-stigma refers to the negative beliefs and behaviours belonging to the individual themselves and has been defined as the reduction in a person's self-esteem or self-worth due to the belief that they are socially unacceptable (Vogel et al., 2007). Finally, affiliate or associate stigma is experienced by those who have a close connection with a stigmatized other, for example parents, spouses, or siblings and can be associated with concealment and shame (Quinn & Chaudoir, 2009).

Internalisation is the hypothesised process in which self-stigma is developed as a result of receiving public stigma. External beliefs and prejudice are turned on the self, resulting in negative self-beliefs, painful emotions, and self-discriminatory behaviours within those labelled as undesirable. For example, internalisation may lead to loss of confidence and self-esteem, undermining the likelihood that an individual will challenge their devalued status (Campbell & Deacon, 2006). This hypothesised process is supported by temporal evidence that public stigma precedes the development of self-stigma (Vogel et al., 2013). These authors reported a cross-lag analysis of a structural equation model to determine the direction of the relationship over time, showing that high public stigma at time one predicted higher levels of self-stigma at time two, but that the reverse was not true.

Watson and colleagues (2007) provide a theoretical model of the internalisation process of stigma related to mental health difficulties. They describe a three-stage process, beginning with *stigma awareness* (or perceived discrimination) which is followed by *stereotype agreement,* in which the individual endorses the publicly held view. The authors argue that self-stigmatization occurs at the third stage, *stereotype self-concurrence*, in which the individual applies these internalised public beliefs to themselves; resulting in harm to self-esteem and self-efficacy (Corrigan & Rao, 2012). Of note, reduction in self-esteem has also been identified as a result of perceived discrimination alone, where such anticipated discrimination resulted in stigma internalisation (Link et al., 1989). While Watson et al. (2007) argue that this process merely measures stigma awareness, as opposed to self-stigma per se, Sheehan and Ali (2016) argue that such anticipated devaluation can result in self-stigma in the absence of actual experiences of discrimination. Importantly, it has also been found that the centrality of a person's stigmatized identity, as well as its salience, can act as mediators to the internalisation process, wherein higher centrality and salience increase the likelihood of internalisation (Quinn & Chaudoir, 2009).

Intellectual Disability Stigma and Internalisation. The effect of belonging to a marginalised, stigmatized, minority group has been investigated for a range of attributes deemed as undesirable by broader society. The literature has primarily focussed on mental health difficulties, HIV/ AIDS, certain ethnicities, and sexual orientations (Livingston & Boyd, 2010). The intellectual disability field has received notably less attention in the world of research (Werner et al., 2012) despite being one of the most highly stigmatized groups (Ditchman, et al., 2013). However, the research that has been conducted has consistently found that, for many people with intellectual disabilities, stigma is associated with physical and mental health difficulties (Jahoda et al., 2010), poor wellbeing and self-esteem (Ali et al., 2015), and can severely affect a person's sense of cultural identity (Spassiani & Friedman, 2014). In addition, many people with intellectual disabilities report that they expect the mainstream world to treat them unfairly, based on their previous negative experiences (Logeswaran et al., 2019). Whilst the majority of stigma theory has been based on evidence from the mental health field, there is growing evidence that such theories and models are also applicable to the intellectual disability population (Ditchman et al., 2013; Thoits, 2011).

Intellectual disability is defined as significant cognitive and functional deficits that have their onset during the developmental period and is often associated with difficulties in communication (Boat & Wu, 2015). As such, people with intellectual disabilities face realistic hardships in their everyday lives (Jahoda & Markova, 2004). However, the experience of stigma involving social barriers, abuse, discrimination, and denial of everyday opportunities (Ali et al., 2015) exacerbates and increases the vulnerability of this group. There are many negative beliefs held about the intellectual disability population in western culture (Finlay & Lyons, 2000) and these can be broadly categorised into two opposing yet equally damaging stigmatizing views; that people with intellectual disabilities are dangerous and should be avoided, or that they are incapable and require over-protecting (Jahoda et al., 2010). These opposing views have been further described as a tension between fear and concern (Ditchman et al., 2016).

In relation to labelling and intellectual disability stigma, a recent systematic review of how people with intellectual disabilities form their social identities reported that the majority of people were aware of their intellectual disability label as well as the negative connotations associated with it (Logeswaran et al., 2019). Many reported feelings of shame, embarrassment, dejection, anger, powerlessness, and frustration associated with the label, as well as a conflict between accepting and rejecting it, while others reported concealment or distance seeking. On one hand, rejection and distance may be evidence that some people did not see the label as relevant to them in constructing their identity. However, importantly, these responses may also be further evidence that individuals were aware of the negative associations of this threatened identity, and therefore enacted these responses as a coping mechanism to manage such threat (Logeswaran et al., 2019).

Given that most are aware of their intellectual disability label and society's negative attitudes and behaviours towards them, it is unsurprising that social comparison has been identified as a key process in how the stereotyped beliefs of society impact self-esteem, during the development of intellectual disability self-stigma (Dagnan & Sandhu, 1999). Negative or upward social comparison increases the likelihood of self-stigmatization, as these appraisals result in the person with intellectual disabilities being perceived more negatively than the general population (Finlay & Lyons, 2000). Degree of perceived intellectual disability stigma has also been associated with low self-esteem in this self-comparison process (Paterson et al., 2012) and it has further been found that core negative beliefs about the self in people with intellectual disabilities are directly related to the experience of feeling different (Dagnan & Waring, 2004). Therefore, there is evidence to support the use of the social-cognitive model of internalisation proposed by Watson et al. (2007) to the intellectual disability population (Sheehan & Ali, 2016).

Stigma Resistance

Stigma has been associated with poor outcomes in mental health, wellbeing, and self-esteem through the theorised process of internalisation. However, the association between public and self-stigma is only moderate (Thoits, 2011), meaning some individuals who are subjected to stigma do not internalise such beliefs. Research suggests that, as opposed to being diminished by stigma, many people can become righteously angry because of the prejudice and unfair treatment they have experienced (Corrigan & Watson, 2002a). In some instances, negative social representations may jar with a person's view of themselves, leading to the renegotiation of previously stigmatized representations in a more positive light (Campbell & Deacon, 2006). Corrigan and Watson (2002a) suggest a continuum of responses from self-stigma to empowerment, which includes righteous anger directed at those who have unjustly labelled them and is considered a healthy response to discrimination. As such, in an opposite process to internalisation, stigma resistance has been positively correlated with self-esteem, empowerment, and quality of life (Sibitz et al., 2009), as well as with social functioning and problem-centred coping (O'Conner et al., 2018).

In a key theoretical paper on stigma resistance, Thoits (2011) defines resistance as the opposition to a harmful force or influence. She describes five available responses that stigmatized individuals may enact: self-stigmatization, deflection, avoidance, self-restoration, and challenging. Of these, challenging and deflection are identified as methods of resistance, as the other responses accept the stigma encountered as valid. Challenging is described as a response which pushes back against the stigma and disrupts social order, whereas deflection responses harden the self against stigma to minimise negative psychological effects, while maintaining social order. There is growing evidence in support of this theory, most notably from Firmin et al. (2017) who defined resistance as the ability to hold a positive illness identity using one's own skills, knowledge, and experience. Of note, Firmin and colleagues highlighted that stigma resistance is not an end state of absent self-stigma, but an active, multifaceted, and ongoing process in which the attitudes and actions of others are continually resisted. In further support of Thoits' (2011) theory, challenging and deflecting resistance processes were found to be enacted by the parents of children with disabilities (Manago et al., 2017). In this study, parents used certain disability discourses to resist and directly challenge the affiliate stigma they received in response to having a child with a disability.

Intellectual Disability and Stigma Resistance. When considering resistance to public intellectual disability stigma, it has been found that the self-concept of people with intellectual disabilities is created by self-agency, as well as the internalisation of the views of others (Jahoda et al., 1988). People with intellectual disabilities often consider the label unimportant, and focus on other, more positive attributes, roles, and competencies to describe themselves (Logeswaran et al., 2019). As such, even when aware of their stigmatized status, many people do not accept a predominantly negative view of themselves (Jahoda et al., 1988).

Despite appearing to be one of the most stigmatized groups, people with intellectual disabilities are able to make saliant certain aspects of the social world to compare themselves to, in order to present themselves in a positive light (Finlay & Lyons, 2000). Such flexibility in social comparison provides an individual with a choice of who to compare themselves with, depending on the dimension in question. In an opposite process to upward social comparison, positive or downward social comparison can protect against the development of self-stigmatization (Finlay & Lyons, 2000). Therefore, comparing themselves favourably to their peers, and laterally to the general population, individuals can protect their sense of self from the societal beliefs about those with intellectual disabilities (Crabtree, 2016). However, when considering the three-stage internalisation model, one could argue that downward social comparison (particularly in relation to behaviour and capability), indicates that *stereotype-agreement* may still be taking place and that resistance is being enacted at the *stereotype self-concurrence* stage. The individual is resisting the application of negative stereotypes onto themselves by seeking distance but is not resisting the validity or applicability of the stereotype to the wider intellectual disability population.

When considering resistance as developing a positive self-identity (Firmin et al., 2017), holding positive beliefs about people with intellectual disabilities may be a more effective form of resistance, compared with downward social comparison, which risks isolation from both in-group and out-group members. Again, when considering the three-stage internalisation model, developing a positive self-identity would indicate that resistance is taking place at the *stereotype-agreement* stage and therefore challenges the negative view of people with intellectual disabilities as a whole. This may include acts of self-advocacy, as minority group membership has also been reported to protect against stigma internalisation (Anderson & Bigby, 2015; Branscombe et al., 1999).

Rationale

The literature demonstrates that the way in which a person belonging to a marginalised group responds to stigma can mediate the impact such stigma has on their sense of self. Therefore, there is value in producing a tool to assess responses to intellectual disability stigma, in order for the effect of stigma to be investigated in this highly stigmatized group.

Research Aims and Hypothesis

The aim of this study was to develop the new Responding to Intellectual Disability Stigma (RIDS) tool and investigate its feasibility, in order to advance our understanding of how stigma is responded to, and its impact on individuals' sense of self. An overarching aim of this study was to produce the new measure in collaboration with people with intellectual disabilities, so that it could be of most use to those in this marginalised group, in clinical and research settings. The first hypothesis for the study was that different ways of responding to intellectual disability stigma could be reliably assessed using the RIDS. The second hypothesis was that stigma responses would predict scores on wellbeing and self-esteem, whereby resisting responses would predict higher levels of both constructs.

Method

COVID-19 Amendments

Originally, this project was designed to be conducted face-to-face with people with intellectual disabilities who were participating in a stigma intervention feasibility study: the Standing Up for Myself (STORM) project. This intervention was designed to support people with intellectual disabilities to learn ways of managing unfair treatment. The RIDS constitutes an essential part of the evaluation of this group, in order to examine how participants respond to stigma, and if this changes over the course of the intervention. STORM was designed to be conducted in pre-established groups with training provided to group facilitators by the UCL Unit for Stigma Research (UCLUS) team and the intervention was due to begin in April 2020. However, due to the COVID-19 pandemic, face to face research was halted nationally. Therefore, ethical approval was sought for an amendment to move this project online to allow the RIDS to be created and psychometrically assessed prior to the re-commencement of the STORM study.

Participants

Recruitment

Using volunteer and snowball sampling, participants were recruited via online advertisements circulated through social media and third sector organisations throughout the UK. In addition, 23 intellectual disability organisations identified through internet searches were contacted directly via email. The advertisement was in Easy Read format to reflect the ethos of the study being one of empowerment and inclusion and provided an email address for further contact (Appendix A). An Easy Read Information Sheet was provided to individuals and organisations who expressed initial interest (Appendix B). The majority of contact was conducted with group facilitators who supported groups for people with intellectual disabilities, who acted as mediators in the recruitment process. Where groups expressed an interest, the researcher met with the group virtually to explain the project in detail. If group members decided they would like to take part, further individual videocalls were organised in order to assess capacity to consent, and to undertake the project in full. Four individuals not associated with a group responded directly through social media and the same information giving and capacity to consent processes were followed with these individuals. See Appendix C for a copy of the consent form.

Participant Demographics

The participation inclusion criteria were that those taking part live in the UK, be over 16 years old, have a mild to moderate intellectual disability (defined administratively as either having a formal diagnosis or being in receipt of special services), and have sufficient verbal communication skills in English to consent and engage in the tasks. Access to a videocall platform and internet was also required. This was a novel, exploratory, quasi-experimental study, and consequently a power analysis was not indicated or possible to produce.

The final study participants were 30 adults with intellectual disabilities. Demographic and other relevant information was collected before the study measures were completed which included age, gender, living situation, ethnicity, schooling, and whether or not participants attended a self-advocacy group (see Table 1). Intellectual disability was assessed initially via an individual identifying as such, given that study participants were self-selecting. Intellectual disability was further assessed by association with an intellectual disability organisation or support group (including liaison with support workers and family members in the recruitment process). In addition, participants were asked about receipt of social care support including intellectual disability support workers, day centres, and supported housing. Finally, possible attendance at a special needs school as a child was also used to assess participants' intellectual disability. The resultant sample were a mostly homogenous group in terms of cognitive impairment and would meet criteria for the mild to moderate intellectual disability population. All participants received social care support for their intellectual disability needs and were able to verbally communicate this to the researchers in their descriptions and understanding of their additional needs. The age of participants ranged from 24 to 74 years with a mean of 39.5. A 31st participant began the study but was unable to fully understand the Likert scale method of answering questions. Therefore, the assessment was discontinued, and responses removed entirely from the dataset.

Materials

Measures

Responding to Stigma – The RIDS. Intellectual disability is defined by deficits in adaptive and intellectual functioning, which includes reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience (Boat & Wu, 2015). As such, there is a need for creative methods to be used in research with people with intellectual disabilities, so that their voices may be heard (Pert et al., 1999). A number of previous studies have reported the success of a procedure described as the 'picture-story task'

Table 1

Participant Sociodemographic Information (N = 30)

Sociodemographic Characteristic	*n*	%
Gender		
Male	19	63.33
Female	11	36.67
Living Situation		
With family or parents	10	33.33
Supported living	8	26.67
On my own	8	26.67
With a partner	3	10
With other people	1	3.33
Ethnicity		
White British/ White European	26	86.67
Asian British	3	10
Mixed Ethnicity	1	3.33
Schooling		
Special Needs School only	13	43.33
Mainstream School only	10	33.33
Both Mainstream and Special Needs School	7	23.33
Member of Self-Advocacy Group		
Yes	23	76.67
No	7	23.33

to reliably elicit cognitive, behavioural, and affective responses from individuals with intellectual disabilities in situations involving threat and aggression (Esdale et al., 2015; Jahoda et al., 2006; Kirk et al., 2008; Pert et al., 1999; Pert & Jahoda, 2008). This procedure was built on the earlier work of Dodge and Frame (1982), who reported the success of this method in eliciting beliefs about aggression in children. This method has also been shown to be effective in supporting people with intellectual disabilities to take turns in hypothetical social scenarios in order to elicit the perceived intent of the other (Pert et al., 1999). Therefore, there is scope in using this method to investigate stigmatizing interactions, as both aggression and stigma are theorised as social-cognitive constructs.

The picture-story method involves verbally presenting participants with a hypothetical vignette of a social interaction, supported by a storyboard of photographs to help scaffold understanding. The vignettes are written in the first-person, present tense, in order for the individual to immerse themselves in the scenario and imagine the described events happening to them (Esdale et al., 2015). Participants are then asked a number of open-ended questions regarding how they would respond in each scenario, including their perception of the event and how they might react. Negative social situations are interspersed with positive ones, in order to reduce the likelihood of a negative response set. Upon completion, participants are also asked about a recent positive experience they have encountered and reminded that the stories were fictional, in order to prevent them ruminating on social injustice or events that might have resonated with their own experiences.

Previous authors stressed the importance of creating such tasks with input from people with intellectual disabilities (Jahoda et al., 2006). As such, the negative social situations in the RIDS were created following a literature search of the types of stigma reported by people with intellectual disabilities in previous studies. This search identified that the negative experiences reported in the literature arising from intellectual disability stigma can be broadly categorised as verbal and physical abuse, social exclusion, avoidance/ social distance, infantilisation, denial of everyday opportunities, denial of autonomy, and denial of capability (Cooney et al., 2006; Corr McEvoy & Keenan, 2014; Ditchman et al., 2016; Dovidio et al., 2000; Jahoda et al., 2010; Logeswaran et al., 2019).

Initial draft vignettes were created from these categories which were designed to elicit a range of responses in order to capture as much variety as possible from those taking part. This design process included following the Easy Read accessibility guidelines (Department of Health, 2018), which include using simple and straight forward language, short sentences, and the inclusion of photographs to support the point being made in the text. It was also important that the scenarios depicted would not be so negative or abusive as to elicit unmanageable or unfair degrees of emotion in those taking part. This was discussed with the STORM research team before the initial draft vignettes were discussed with the STORM Expert Advisor Group; five adults with mild to moderate intellectual disabilities who were employed to consult on the development of the STORM study. The group gave their advice and opinions regarding the type of stigmas to be included in the RIDS, including the likelihood of the depicted events occurring and how true to real life these were. Following this, a further expert by experience group, the Mencap Research Forum, were then consulted with to discuss the specifics of the vignettes. This group consisted of approximately 10 men and women with mild to moderate intellectual disabilities who were employed by Mencap to consult with different research groups working in this field. Discussions included the appropriateness and understandability of the wording and photographs used in the RIDS. A key outcome from this meeting was the decision to use the term ‘story’ (as opposed to vignette or scenario) and changing some of the photographs which were considered too emotive. For example, removing a photograph in which the participant was pointed and laughed at by a friend, as the group felt this could be perceived as overly aggressive and upsetting. Following input from these expert-by-experience groups, the final five vignettes agreed upon covered denial of autonomy, denial of capability, verbal abuse, infantilisation, and social exclusion. . This first draft of the RIDS was finally further discussed with the wider STORM study management group before agreeing that it was appropriate to move forward with to data collection. The study management group consisted of researchers and lecturers from UCL and Cardiff University, who have been involved in the development and application of the STORM intervention programme.

Bearing in mind the previous literature on picture-story tasks, intellectual disability stigma, and consultation with experts-by-experience, the final RIDS tool included six hypothetical vignettes of everyday encounters between a person with an intellectual disability and a member of broader society. Five vignettes depicted scenarios in which the participant was faced with varying degrees of unfair treatment, and one of being treated fairly. All vignettes were written in the first-person, present tense and were each supported with two photographs, which were presented to participants at specific points in the scenario, indicated in the script by a prompt to the researcher. Participants were instructed to imagine themselves as the main character in each vignette, before answering questions regarding their response. For example, the second vignette of the RIDS reads "(Photo 2a) You are at a college course. (Photo 2b) You are having a cup of tea with some friends in the café at lunchtime. They start talking about looking for jobs. You tell them that you would like a job too. One of them says "*you'll* never get a job". Following the presentation of each vignette, participants were asked six, open-ended questions related to how they would respond in the presented scenario. This included affective, cognitive, and behavioural responses, as well as the motivation behind their chosen behavioural response. For example, to elicit their perception of the scenario, participants were asked "How do you think your friend is treating you when they tell you that you cannot get a job?". The responses to questions were recorded on a digital voice recorder for later transcription and coding. See Appendix D for a copy of the RIDS vignettes, supporting photographs, and questions.

Other Measures. Previously, it has been shown that the construct of stigma is closely related to the constructs of self-esteem and psychological wellbeing. Therefore, established 'gold standard' measures of these constructs were also completed by participants, in order to assess the concurrent validity of the new RIDS measure.

Self-Esteem. The Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965) is the most widely used assessment of the self and has also received the most amount of psychometric analysis and validation than any other measure of self-esteem (Robins et al., 2001). The original measure included ten items, five positive and five negatively worded, answered on a four-point Likert scale of agreement from ‘strongly agree’ to ‘strongly disagree’. There is evidence that brings into question the clinical and research effectiveness of the original RSES with participants who have intellectual disabilities, as it has been found that the measure has poor internal reliability and criterion functioning when answered by individuals from this population (Davis et al., 2009). However, a later Rasch analysis of the scale’s psychometric properties concluded that item fitness and difficulty, rating scale analysis, and reliability outcomes, all indicated that it was an appropriate measure to use with this population when assessing self-esteem (Park & Park, 2019). A number of studies report the efficacy of using an adapted version of the RSES produced by Dagnan and Sandhu (1999) for people with intellectual disabilities (Paterson et al., 2012). This adapted version is based on a later version of the original RSES (Rosenberg, 1982). It has six items (four positively and two negatively worded), simplified language, and includes a visual aid to help represent the Likert structure from one to five, indicating increasing levels of agreement with each item. For example, “I feel that I am a good person, as good as others”. The adapted version (Appendix E) is reported to also have a two-factor structure of positive and negative self-esteem, in-line with the original (Dagnan & Sandhu, 1999). However, there is debate in the literature as to whether the two-factor structure is the result of a wording effect of the positive and negative items, as opposed to positive and negative self-esteem (Greenberger et al., 2003). In the current study and the STORM intervention study, the response scale was simplified to four options from ‘never’ to ‘always’, following extensive consultation with people with intellectual disabilities. Each item is scored from zero to three, resulting in a range of total scores from zero to 18.

Psychological Wellbeing. The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007) is a 14-item, positively worded measure of psychological wellbeing. It has since been reported to be reliable, valid, and acceptable, making it popular in wellbeing intervention studies (Maheswaran et al., 2012). It is answered on a five-point Likert scale of agreement to statement items over the previous two weeks from ‘none of the time’ to ‘all of the time’ and as such, a higher score indicates better wellbeing. Subsequent confirmatory factor analysis has shown that it measures a single underlying construct (Tennant et al., 2007). However, a later Rasch analysis by the same authors found that some items had a bias for gender and age, resulting in an alternative, seven-item version being created (Stewart-Brown et al., 2009). Of note, the authors commented that there was still value in using the original version in order to explore these biases further in different populations. The original version is also reported to be responsive to change at the population, group, and individual level (Maheswaran et al., 2012). The WEMWBS has not yet been validated for use with the intellectual disability population, though the items have been reported to have good readability (Daery et al., 2013). However, these authors also concluded that, based on a Mokken scaling analysis, people with lower cognitive ability may find some items difficult to differentiate. Although the authors did not define what constituted ‘low cognitive ability’ this has implications for use with the intellectual disability population. A subsequent adapted version for people with intellectual disabilities has since been created (WEMWBS-ID; Scior et al., in preparation; Appendix F) and this version includes simplified language, for example amending ‘I’ve been feeling optimistic about the future’ to ‘I felt hopeful about the future’, as well as a reduced Likert scale to four points, alongside a visual response aid. This version also includes practice items to check user understanding and the referent time scale has been reduced from the preceding two weeks to one week, following consultation with people with intellectual disabilities.

Software

Software programmes were required to support the project, following its move to online data collection. Ethical approval was gained for the use of Microsoft Teams, Zoom, or Skype for communication with participants and each person was asked which platform was most accessible for them. The demographic, WEMWBS-ID, and RSES questions, along with the accompanying response aid, were transferred to the Qualtrics platform; an online survey provider which provides electronic recording and secure storage of data. The screen-share function of the online platforms was used to display the Qualtrics survey. Finally, an online transcription service was required for the initial recordings to be transferred into text, for later coding. The service chosen was Otter.ai due to accuracy of transcription, ease of use, and low cost. SPSS version 27 was used for statistical analysis.

Participant Resources

Participants were provided with information and resources on how to stand up for themselves in the face of stigma upon completing the study, to compensate them for their time in taking part (Appendix G). If an individual had consented to take part but was unfortunately unable to complete the task due to complexity, they were also provided with the resources to thank them for their time.

Procedure

Data Collection

Following recruitment, information giving sessions, and obtaining informed consent, participants were met individually on a videocall to collect all data. As well as being able to see the questions themselves via the screen-share option, participants were read the questions aloud by the researcher to ensure understanding. Their answers were electronically recorded by the researcher on the Qualtrics website, which participants could see via the screen-share function. Demographic information was initially collected, before moving onto practice questions to orientate participants to the Likert scale format, which was also supported with a visual aid depicting the difference between response options (Appendix H). Following this explanation, if participants understood the answering method, the survey moved on to the WEMWBS-ID and adapted RSES. Answers were recorded on Qualtrics using an anonymised participant code. Next, participants were offered a break and asked if they wished to continue to the RIDS. The explanation was read to them again with a reminder that they could end the interview at any time, and a close supporter was identified in the event they required additional emotional support. The researcher then began recording the RIDS interview on an electronic voice recorder, shared the storyboard photographs via screen-share and read the vignettes aloud from a script, before asking the open-ended questions. Upon completion, participants were reminded that the stories were fictional and asked about a recent positive experience. Their mood and wellbeing were assessed before ending the call. They were then emailed the 'Standing up for Myself' resources to thank them for their time.

Research Design and Analysis

This novel, exploratory, feasibility study followed a quasi-experimental, mixed-methods design. The independent variable was responses to stigma, and the dependent variables were wellbeing and self-esteem. The RIDS data were examined using content analysis, a bottom-up approach which sits halfway between quantitative and qualitative analysis, by creating a typology of responses from qualitative data, which are then quantified for further analysis (Esdale et al., 2015). All 30 transcripts were searched for phrases under the categories of emotion, cognition, behaviour, and motivation in response to each scenario. This resulted in 480 response phrases that were coded into typologies for each of the four categories, resulting in four categorical subscales: the RIDS-E (emotions), the RIDS-C (cognitions), the RIDS-B (behaviours), and RIDS-M (motivations). For the purpose of coding, emotions were defined as a ‘feeling or inner state in response to a situation’, cognitions as the ‘activity of knowing, learning and thinking’ and behaviours as ‘a specific, goal-directed action between the individual and the event which preceded the emotion’ as described by Plutchik (2001) in his writings on the psycho-evolutionary theory of emotions. Motivations were defined as ‘a drive or need that desires a change, either in the self or the environment’ (Reeve, 2014). Considering these definitions, responses were only coded if they were directly related to the interaction depicted in the scenario. If not, they were labelled as uncoded. Ambiguous responses were also labelled as uncoded in order to ensure as much as possible that the approach remained bottom-up and did not over-interpret participant responses. In instances where more than one response was given under a particular category, the first response was chosen for coding, unless a later utterance was given by a participant to correct themselves or clarify the initial response. Response categories were then compared to WEMWBS-ID and RSES scores to investigate the relationship between responses to stigma, wellbeing, and self-esteem.

Ethics

Ethical approval was originally in place for this project as part of the wider STORM study. However, as stated above, an amendment was sought in response to the COVID-19 pandemic in order to move recruitment and data collection online and conduct this separate from the STORM study which had been paused. Appendix I includes the approved amendment proposal, and Appendix J contains confirmation of approval from the ethics committee.

There were two main ethical concerns in this study; the capacity to give informed consent, and the possibility of eliciting painful emotions within participants and how these might be managed remotely. These concerns were addressed by ensuring participants received accessible information about the study, which was explained in a simplified manner, and with support from someone they knew well if necessary, to help them understand the potential advantages and disadvantages of taking part. Potential participants were then given at least 24 hours to consider if they wanted to take part and to discuss participation with trusted others if desired. Participants were also reminded at several points that taking part was a choice and that they could change their mind at any time.

With regards to managing painful emotions, participants were informed that some vignettes might cause them to feel sad or upset and that the researcher would support them if this occurred. Rapport was also built during the recruitment process by meeting with groups and individuals before data collection, so that participants would feel more able to disclose if they were in distress. A trusted supporter was also identified before the task took place, so that the researcher could support the participant in contacting them, should they become upset. Participants were also reminded that they could have a break at any time and their wellbeing was continually assessed by the researcher. At the end of the task, participants were reminded that the scenarios were fictional and asked about positive social experiences they may have had recently.

Results

Feasibility of the RIDS

As previously noted, only one participant was unable to complete the study due to its complexity, suggesting that this method of eliciting responses to stigma may be feasible for the mild to moderate intellectual disability population. Further use of the RIDS in the upcoming STORM intervention study will allow for further testing of this, with a larger and broader sample.

With regard to completion time, the average time taken to complete the RIDS was 25.73 minutes, with a range of 17-49 minutes and a median of 23.5. The high-end outliers reflect participants providing additional and supporting information as to the chosen response, including personal stories of how they had dealt with similar scenarios in the past. In order to ensure coding was as fair as possible, and did not privilege longer or more detailed answers, only the first response was coded, thereby making this additional information redundant for coding. In addition, it appears that scenario five (infantilisation) was often experienced as confusing by participants. Responses were often unrelated to the discrimination the researchers intended to depict and related instead to other aspects of the scenario. Scenario five did also not elicit any novel responses in relation to stigma and, therefore, was not included in the analysis.

Categorising Responses to the RIDS

Having removed scenario five from the analysis, and scenario three not being included due to being a distractor item, four stigmatizing scenarios were included in the final RIDS analysis. These depicted: denial of autonomy, denial of capability, verbal abuse, and social exclusion.

In line with the content analysis procedure, initial typologies were first identified per category (emotion, cognition, behaviour, and motivation), per scenario and can be seen in Appendix K. Across the four scenarios, there was most consistency in the emotions reported by participants, which mostly reflected feelings of sadness and anger. With regard to the thoughts, behaviours, and motivations, there was a wider range of responses across the different scenarios depicted, which reflected the different contexts in each story. In order for the RIDS to be most useful in terms of consistency and replicability, a single overall coding frame was required which encapsulated all the responses seen across the scenarios, condensed into fewer, broader categories. A single coding frame would also be most useful, given that some responses were only seen once in one scenario but frequently in another, meaning that such a response could be coded for any story, even when only appearing with a low frequency.

Appendix L includes the initial overall coding frame, which demonstrates the combination of several of the individual typologies into broader codes. No changes were made to the emotion typologies, as these were consistent across the scenarios, where the range of feeling words present in the dataset were grouped under their core feeling, following Plutchik's (2001) categorisations. With regard to cognitions, there were a range of responses which identified that the treatment was unfair, including that it was bad, wrong, unkind, and constituted discrimination. These responses were grouped together as many participants used several of these words in a single response. The category 'deemed incapable' was included to reflect responses which identified the treatment not only being unfair, but that it reflected the other character in the scenario underestimating the participants' ability, which is a key component of intellectual disability stigma. The behaviours of 'complain', 'report', and 'seek support' were condensed into one category, to reflect a reaction which recruited another into their behavioural response. An important distinction was made between the behaviours of 'leave' and 'do nothing' in order to reflect the active or passive nature of the response, in that the action of leaving was a more confident response to remove oneself from the situation, whereas doing nothing reflected a response which recognised the unfair treatment but chose to make no action. A further behavioural response of 'no need for action' was included when participants felt that the treatment received was fair, and therefore did not require a response. Similarly, the motivation categories of 'maintain status quo' and 'avoid escalation' were condensed into the broader category of 'avoid' to reflect a response which aimed to deescalate the situation in an appeasing manner. A range of motivations which reflected a resisting response were identified from the individual scenarios, including 'assert rights', 'change behaviour' and 'educate'. As such these were condensed into the category of 'challenge' to reflect the motivation being one of standing up to the unfair treatment depicted in the scenarios.

Inter-Rater Reliability

Having created the initial overall coding frame (Appendix L), reliability was necessary to assess, to ensure that the responses would be coded in the same way by different researchers. The initial coding frame and dataset were given to a second coder, who was familiar with the study but had not been involved in data collection. The four response categories were randomised across the four scenarios to reduce assumptions being made regarding a participant's response in one category, based on another. Inter-rater reliability was assessed using Cohen's kappa (k) which analyses the precision between two coders by calculating likelihood of agreement, over and above chance. Results showed moderate agreement and above across the four categories, using the more stringent interpretation suggested by McHugh (2012): RIDS-E $k = .925$, $p < .001$ (almost perfect); RIDS-C $k = .771$, $p < .001$ (moderate), RIDS-B $k = .875$, $p < .001$ (strong), RIDS-M $k = .783$, $p < .001$ (moderate).

Cross-tabulation showed several instances of disagreement between two typologies within the motivation category, 'feel better' and 'avoid'. It appeared that several responses implied that participants would avoid a situation in order to feel better. As such, the descriptions and labels were further refined and defined, with 'avoid' being amended to 'protect' in order to differentiate the motivation behind the avoidance either being one of restoring the self following painful emotions (i.e. feel better), or to reduce the likelihood of further harm (protect). Motivations were then re-coded based on the updated coding frame (Appendix M) and Cohen's kappa showed improved agreement, RIDS-M $k = .823$, $p < .001$ (strong). Discrepancies across the other categories were more dispersed and so were discussed between the coders to agree on the final typology coding. Table 2 shows the frequency of typologies per

Table 2

Frequency of Category Typologies in the RIDS

Category	**Typology**	**Scenario 1**	**Scenario 2**	**Scenario 4**	**Scenario 6**	**n**	**%**
Emotions	Content	3	0	0	0	3	2.50
	Ambivalent	0	1	1	2	4	3.33
	Sad	4	**19**	**18**	**18**	**59**	**49.17**
	Fearful	3	1	5	2	11	9.17
	Angry	**15**	5	6	5	31	25.83
	Uncoded	5	5	0	3	13	10.83
Cognitions	Fair	4	0	0	1	5	4.17
	Indifferent	0	1	3	3	7	5.83
	Unfair	**21**	**23**	**26**	**23**	**93**	**77.50**
	Deemed incapable	4	4	0	0	8	6.67
	Endorsing	0	2	0	1	3	2.50
	Uncoded	1	0	1	2	4	3.33
Behaviour	Speak Up	**17**	**14**	2	**15**	**48**	**40.00**
	Report	2	7	8	2	19	15.83
	Prove Wrong	0	4	0	0	4	3.33
	Leave	0	3	5	5	13	10.83
	Nothing	10	2	**15**	6	33	27.50
	Uncoded	1	0	0	2	3	2.50
Motivation	Challenge	**18**	**16**	3	**18**	**55**	**45.83**
	Feel Better	2	1	5	5	13	10.83
	Punish	0	2	5	0	7	5.83
	Protection	3	3	**14**	2	22	18.33
	Resignation	2	1	2	0	5	4.17
	No need for action	1	1	0	2	4	3.33
	Uncoded	4	6	1	3	14	11.67

category, per scenario. The most frequently reported emotion across the scenarios was sadness, which was the most frequently reported in all scenarios except for scenario one (denial of autonomy), in which anger was the most frequently reported emotion. The highest frequency cognition across all scenarios was that of the treatment received being viewed as unfair. The most frequent behavioural response overall was to speak up. This was true for all except scenario four (verbal abuse), in which the majority of participants reported they would do nothing. Similarly, the most frequent motivation was that of challenging, except in the scenario of verbal abuse, where most participants reported self-protection as the motivation behind their behaviour.

To investigate the relationship between the RIDS categories, multiple two-sided Fisher's exact tests of independence were conducted. Fisher's exact tests were used, rather than Pearson's Chi-Squared, due to some cells containing samples of less than 5. A Bonferroni adjusted alpha of .0125 (.05/4) to control for inflated Type 1 error during multiple comparisons was also used. The results displayed in Table 3 show that there was a significant relationship between the emotion and cognition categories, emotion and motivation categories, and behaviour and motivation categories. The Bonferroni adjustment is considered conservative by many (Armstrong, 2014), and therefore the relationship between cognition and motivation categories may also be of relevance.

Table 3

Fisher's Exact Test Significance Between RIDS Categorical Subscales

Subscales	RIDS-E	RIDS-C	RIDS-B
RIDS-C	$p < .001$**	-	-
RIDS-B	$p = .279$	-	-
RIDS-M	$p = .003$**	$p = .014$*	$p < .001$**

* *Significant at the .05 alpha level*
** *Significant at the .0125 alpha level*

Scoring Responses to the RIDS

In order for results from the RIDS to be compared to other measures, as well as to assess any change over time, the categorical codes were further transformed into numerical scores. This was achieved by allocating each typology a score, on a scale of -1 to +1, resulting in an overall score of -4 to +4 per subscale (see Table 4).

The emotions scoring method was based on the evolutionary emotions theory and functional framework proposed by Plutchik (2001) and his conceptualisation of the 'emotions

Table 4

RIDS Scoring Frame Based on Category Typologies.

Category	Typology	Scoring	Response Type
Emotion	Content	+1	Positive
	Ambivalent	0	Neutral
	Sad	-1	Negative
	Fearful	-1	Negative
	Angry	-1	Negative
	Uncoded	*0*	*Uncoded*
Cognition	Unfair	+1	Resisting
	Deemed Incapable	+1	Resisting
	Indifferent	0	Neutral
	Fair	-1	Internalising
	Endorsing	-1	Internalising
	Uncoded	*0*	*Uncoded*
Behaviour	Speak Up	+1	Resisting
	Report	+1	Resisting
	Prove Wrong	+1	Resisting
	Leave	0	Neutral
	Nothing	-1	Internalising
	Uncoded	*0*	*Uncoded*
Motivation	Challenge	+1	Resisting
	Punish	+1	Resisting
	Feel Better	0	Neutral
	Protection	0	Neutral
	No Need for Action	-1	Internalising
	Resignation	-1	Internalising
	Uncoded	*0*	*Uncoded*

wheel'. This identifies eight core human emotions, between which there are further, mixed emotional responses with varying degrees of similarity between them, as well as a third dimension which depicts the intensity of the emotion experience. This framework was used in the current study, firstly, to categorise the broad range of verbal responses into their appropriate primary emotional dimension, and secondly, to score these in terms of positive and negative experience. Therefore, pleasant emotions on the RIDS were allocated a positive score, ambivalence, or lack of feeling a neutral score of zero, and negative emotions allocated a minus score.

The scoring method for the other three subscales was based on the previous stigma literature by Corrigan and Watson (2002a) and Thoits (2011) with regard to responses to stigma and how these may be considered to sit on a continuum from resisting to internalising. Resisting responses were awarded a positive score, internalising responses a negative score, and ambivalent or indifferent responses a neutral, zero score. As such, negative scores on the RIDS-C, RIDS-B, and RIDS-M indicated an internalising response type, while positive scores indicated a resisting response type. It was hypothesised that higher scores on these subscales would correlate with higher scores of wellbeing and self-esteem. Across all four subscales, uncoded responses were awarded a score of zero, so as not to affect the final score.

Descriptive statistics showed that participants typically reported an overall negative emotional response (RIDS-E; *M* = -3.2, *SD* = 1.07) and resisting cognitions (RIDS-C; *M* = 3.1, *SD* = .88) across the four scenarios. Behaviours and motivations were also somewhat resisting, but to a lesser degree than cognitions (RIDS-B; *M* = 1.3, *SD* = 2.09; RIDS-M; *M* =1.7, *SD* = 1.45). Table 5 shows the means and standard deviations for the RIDS subscale scores, per scenario. Scenario four (verbal abuse) elicited the strongest negative emotional response, but also the least resisting behaviours and motivations. Scenario two (denial of capability) elicited the highest level of resisting behaviours.

Psychological Wellbeing and Self-Esteem

The WEMWBS-ID includes 14 items answered on a four-point Likert scale of one to four. However, the scoring method for the original WEMWBS uses a five-point Likert scale of one to five with a range for the total score of 14 to 70. In order for results of the WEMWBS-ID to be comparable to scores on the original WEMWBS, scores from the current study were transformed from a four- to five-point scale. This was done by first performing a linear transformation to a scale of zero to one, before transforming again to a scale of one to five.

Table 5

RIDS Subscale Scores per Scenario

RIDS Scenario	RIDS-E	RIDS-C	RIDS-B	RIDS-M
Scenario 1 Denial of Autonomy				
Mean	-.63	.70	.30	.50
SD	.66	.71	.95	.68
Scenario 2 Denial of Capability				
Mean	-.80	.83	.77	.53
SD	.41	.53	.57	.63
Scenario 4 Verbal Abuse				
Mean	-.97	.87	-.17	.20
SD	.18	.35	.91	.55
Scenario 6 Social Exclusion				
Mean	-.83	.70	.37	.55
SD	.38	.60	.81	.63

Mean scores range from -1 to +1

Table 6 shows the original and transformed scores. Results showed that the transformed scores on the WEMWBS-ID ranged from 29.97 to 65.99 with a mean of 46.49 (*SD* = 8.99). It has been suggested (Warwick Medical School, 2021) that scores may be categorised into low (14-42), average (43-59), and high (60-70) wellbeing. Given these cut-off points, three participants (10%) scored in the high range, 15 (50%) in the average range, and 12 (40%) in the low range. The WEMWBS is reported to be normally distributed, and the skewness of the distribution of scores in this study indicated a slight right, positive skew but not to a significant degree (skewness = .680).

Results on the RSES ranged from four to 17, with a mean of 12.07 (*SD* = 3.34). The skewness of the distribution indicated a slight left, negative skew but not to a significant degree (skewness = -.549). Scores of wellbeing and self-esteem were found to be positively moderately correlated ($r(28) = .587$, $p < .001$), which indicated that as scores in wellbeing increased, so did self-esteem scores.

Table 6

Transformed WEMWBS-ID Scores

Original WEMWBS-ID Score	Reduced-Scale Score	Transformed WEMWBS-ID Score
1	0	1
2	0.33	2.33
3	0.66	3.66
4	1	5

The RIDS, Wellbeing, and Self-Esteem

In order to preliminarily investigate the possible association between the RIDS and measures of wellbeing and self-esteem, multiple correlations with a Bonferroni adjusted alpha of .0125 (.05/4) were run to compare the scores of the RIDS subscales with the WEMWBS-ID and RSES. A spearman correlation was chosen, as scatterplots indicated that the relationships between the constructs were not linear. Table 7 shows the correlation coefficients and significance values between the measures, which indicate that there were negligible, or very weak, associations between the RIDS subscale scores and the WEMWBS-ID and RSES. None of the correlations reached statistical significance.

Table 7

Spearman's correlation results between the RIDS, WEMWBS-ID, and RSES

RIDS Subscale	WEMWBS-ID	RSES
RIDS-E	r_s (28) = .073, p = .702	r_s (28) = .055, p = .774
RIDS-C	r_s (28) = -.038, p = .842	r_s (28) = .040, p = .835
RIDS-B	r_s (28) = -.026, p = .891	r_s (28) = .209, p = .268
RIDS-M	r_s (28) = .048, p = .802	r_s (28) = .274, p = .142

Discussion

The aim of the current study was to create and test the feasibility and initial psychometric properties of the Responding to Intellectual Disability Stigma tool. The picture-story method used was successful in eliciting responses to hypothetical stigmatizing scenarios. Participants with mild to moderate intellectual disabilities understood the task, could imagine the presented scenarios and themselves within them, and provided appropriate responses to questions asked. Responses ranged in terms of depth and breadth; however, even one-word answers could convey an individual's emotional, cognitive, or behavioural response, and the motivation behind it.

As well as understandability, applicability and usefulness are other important aspects to consider, when assessing feasibility of a new measurement tool. There was a wide range in the time taken to complete the RIDS, which reflected the depth and detail of some participants' responses. While providing interesting and supportive information, this additional detail was not relevant to the final coding or scoring method of the RIDS. This coding method was intentionally chosen to ensure that longer answers were not privileged over and above those who gave shorter responses or who may have had more difficulty with verbal communication. Future use of the RIDS could include an additional score to reflect the richness of responses, for example, number of possible actions that an individual identifies per scenario. This may be useful information in intervention studies, such as STORM, which aim to increase participants' capability to stand up to stigma. Number of possible actions could act as an outcome criterion, with the expectation that engaging in an intervention would increase the number of options an individual has available to them.

As noted in the results section, scenario five was not included in the final analysis, due to eliciting confusion and answers not relating to the intended unfair treatment aspect of the scenario. Removing this scenario would reduce completion time by approximately 17% by removing 1/6 of the materials. In addition, the original version of the RIDS piloted in this study included a number of behavioural questions: 'what would you do', 'what would you do next', and ‘what would you do if it happened again’. The final coding and subsequent scoring frames were based upon participants’ first answers, and so responses to these additional questions were redundant. As such, the final two questions could also be removed from the RIDS protocol, further reducing completion time and concentration time required from participants.

Initial Psychometric Properties

There are three phases when creating a rigorous scale: item development, scale development, and scale evaluation (Boateng et al., 2018). This study was exploratory in nature, and so in-depth statistical analysis would be premature at this stage. However, initial results indicate that the RIDS has strong inter-rater reliability overall, with three of the four categorical subscales showing strong to almost perfect, and one subscale showing moderate, inter-rater reliability. The creation of the scenarios with expert-by-experience groups, the removal of scenario five, and anecdotal feedback from participants indicate that the RIDS has good face validity. The significant correlations between the subscales suggest that response typologies on one subscale are related to the typologies on other subscales. Exploring these relationships further, the strong correlation between the RIDS behaviour and motivation categories would indicate that the action of ‘speak up’ was associated with the motivation to ‘challenge’, and that to ‘do nothing’ was motivated by the need to ‘protect’.

Similarly, the strong correlation between the RIDS emotion and cognition categories indicates that certain emotional responses were associated with certain appraisals. This association indicated that perceiving unfair treatment induced painful emotions in people with intellectual disabilities, for example, feeling sad was most highly associated with the thought that treatment received was unfair. Of note, however, is that whilst the analysis coded the first emotion named by a participant, many reported more than one emotion, and this was often a combination of sadness, fear, and anger. As such, the current results support the idea that unfair treatment elicits a range of negative emotions, and that sadness is the first one brought to mind.

No correlation was found between the RIDS cognition and behaviour categories. Whilst these responses were in relation to hypothetical scenarios and therefore inferences must be drawn tentatively, this may be an indication that a range of behavioural responses can be enacted in response to certain perceptions or cognitions. If so, this result indicates that even when people perceive the treatment they receive as unfair and experience resisting cognitions (as the majority of participants did), this does not always translate into resisting behaviours. Whilst drawing a firm conclusion on this would be premature, it is also supported by the mean high score on the RIDS-C (indicating high resistance) and the comparatively lower mean score on the RIDS-B (indicating mild resistance). When considering the process of resistance (Firmin et al., 2017), this may be explained by participants' ability to differentiate the stigma from their own identity, but not possessing a sense of empowerment, behavioural repertoire, or confidence to resist it. This has important implications for stigma resistance interventions, in that people with intellectual disabilities may already be skilled in noticing unfair treatment but require support in responding in an empowering and self-affirming way.

Differences Between Scenarios

Although there was an overall response pattern across the four scenarios, there were some important differences between the unfair interactions depicted. Scenario one (denial of autonomy) was the only story to elicit the strongest emotion of anger. In this scenario, the participant is ignored by the doctor at their GP appointment. As well as noticing this as unfair, many participants commented that this was poor behaviour from a professional, whose job was to help them. The other scenarios, which included peers, colleagues, and strangers, were most likely to elicit sadness. Therefore, it may be the case that when stigma is enacted by those in a position of responsibility, this is experienced as affrontive and elicits righteous anger (Corrigan & Watson, 2002a).

Scenario four (verbal abuse) was the only interaction most likely to elicit the behavioural response of ‘do nothing’ and motivation of ‘protection’. All others most frequently elicited the responses to ‘speak up’ and ‘challenge’ respectively. In scenario four, the hypothetical verbal abuse was perpetrated by an unknown teenager, and therefore the stranger context of the situation appears to have added a layer of threat to the situation, compared with scenarios where the other was known. Given the reality that people with intellectual disabilities are often the victims of violent hate crimes (Dimensions, 2016), a protective as opposed to challenging response may well be the best course of action in some discriminatory situations.

The RIDS and Stigma Theory

When considering the previous literature further, there was a striking similarity between the RIDS-M categories and Thoits’ (2011) conceptualisation of stigma responses, who identified that a stigmatized individual can: deflect, challenge, self-restore, avoid, or self-stigmatise. Aside from deflection, these responses were also seen in the RIDS-M, where ‘challenge’ and ‘punish’ could be categorised as challenging, ‘feel better’ as self-restore, ‘protection’ as avoidance, and ‘resignation’ and ‘no need for action’ as self-stigmatization. The RIDS did not identify or elicit responses that would be defined as deflection; where the stereotype is agreed with in general but not applied to the individual themselves in a ‘that may be true for some, but not for me’ type response. This finding is also interesting given that a number of previous studies identified downward social comparison as a strategy enacted by people with intellectual disabilities when faced with stigma (Finlay & Lyons, 2000; Jahoda & Markova, 2004; Monteleone & Forrester-Jones, 2016). Downward social comparison and deflection share common characteristics in endorsing the broader negative stereotype but denying that it applies to oneself. An absence of responses that would be categorised as deflection was also reported by Firmin et al. (2017) in their conceptual model of stigma resistance in the mental health field. This may be explained by the high number of self-advocates in the current study, who are likely to reject intellectual disability stigma and its application to everyone in their group, as opposed to only themselves. This may also be a result of the type of questions asked and the scenarios depicting individual discriminating encounters. As the vignettes described the stigma only being directed at the participant, it may be unlikely to elicit a downward social comparison or deflecting response, compared with discrimination directed towards the intellectual disability group as a whole.

Considerations of Content Analysis, Cognitive Ability, and Intellectual Disability

The key underlying epistemology of content analysis is to remain as close as possible to the words that people use in order to ascertain the presence of certain words, themes, or concepts within qualitative data. This includes not over-interpreting or attempting to draw out hidden meaning from the descriptions that people provide. However, an important consideration when analysing narrative data in this way, is the meaning each individual has for the words they use to describe their experience, particularly their emotional experience. For example, one individual reporting that they feel sad may be undergoing a different emotional experience to another individual who also reports feeling sad. Alexithymia is a clinical construct which describes a difficulty in recognising, defining, and communicating one's emotional experience, and there is some evidence that the aetiological factors associated with its development are present in the intellectual disability population (Mellor & Dagnan, 2005). There is also evidence that people with lower scores on the verbal intelligence quotient are more alexithymic (Davies et al., 2015). However, the literature does not yet show that the three key aetiological elements of alexithymia (difficulty identifying emotions, difficulty describing emotions, and externally oriented thinking style and limited fantasy life) are present simultaneously in people with intellectual disabilities (Mellor & Dagnan, 2005).

This poses a methodological and theoretical challenge wherein one stance values the words people use to describe their experiences, while the other questions the validity of such words to describe complex emotional states. The decision in the current study to closely follow the words used by participant was three-fold. Firstly, content analysis is a well-established method and fidelity to the procedure is essential in such statistical analysis. Secondly, this method of analysis has been widely reported as efficacious in intellectual disability research and aggression. It has been shown to be able to differentiate between different groups (Kirk et al., 2008) as well as support people with intellectual disabilities to consistently report emotional and cognitive responses from self-referent and other-referent perspectives (Pert et al., 1999). Thirdly, participants in the current study were able to differentiate their responses to vignettes with differing contexts in terms of danger and the relationship to the ‘other’ in the story, indicating that at least some individuals could imagine a range of emotional responses and communicate them in the RIDS procedure. This is supported by previous evidence that some people with mild and moderate learning disabilities are reliable in their use of sophisticated measures of belief intensity and can easily understand and work with a simple cognitive intervention, including the identification and expression of emotions (Dagnan & Chadwick, 2005). An emotions-based assessment could be used in future studies of the RIDS, to assess participants ability to recognise, verbalise, and differentiate emotions, beyond the initial interview (Dagnan et al., 2000).

Stigma Responses, Wellbeing, and Self-Esteem

The main aim of the current study was to create the RIDS and investigate its feasibility and applicability to the mild to moderate intellectual disability population. The RIDS development is in its very early stages and requires more robust testing now that it has been shown to be feasible and appropriate. When developing a new measure, however, investigating its association with existing measures is an important part of the process and this was achieved by comparing responses to stigma with measures of wellbeing and self-esteem. The current study did not find a correlation between the RIDS, WEMWBS-ID and RSES, indicating that resisting and internalising responses to stigma may both be associated with positive and negative wellbeing and self-esteem. Whilst this possible conclusion requires further investigation, it may be that, in some cases, resisting responses led to positive wellbeing and self-esteem, in that the perceived stigma was not agreed with or internalised, protecting the self (Corrigan & Rao, 2012). This would explain the presence of expected outcomes reported by some participants in the current study. Conversely, as noted by previous authors (Thoits, 2011), not internalising stigma does not always protect an individual from poor self-esteem or wellbeing. Even when stigma is not agreed with or internalised, having to manage it on a daily basis can take its toll on the sense of self of people in marginalised groups. Knowing that the mainstream world treats one unfairly and holds negative perceptions about one (Logeswaran, 2018) is likely to affect one's sense of self, even when such perceptions are not personally endorsed. This may explain why some resisting responses were associated with poor wellbeing and self-esteem. As mentioned above, these results must be interpreted with caution, given the early stage of the RIDS development process. Future investigations of the RIDS would benefit from more robust and in-depth analysis of its outcomes with measures of associated constructs.

Limitations

This study involved hypothetical stigmatizing scenarios. As such, responses were based on how a participant believed they might react in a given situation, rather than an observable, real-life behaviour. In the absence of social pressures, and within the safety of a hypothetical situation, it may be that in the study participants felt more confident to respond in a challenging way to stigma than they would in real life. Therefore, study responses may have been affected by response bias (Lavrakas, 2008) and reflect a truer representation of how a participant would like to respond, as opposed to how they really would. However, this assumption would be difficult to prove without the use of experimental methods, which would be highly unethical, given the content of the scenarios and the almost certainty of causing undue distress. In addition, the difference in resisting behaviours towards the more dangerous scenario of verbal abuse would indicate that participants could differentiate their behaviours in response to the different social contexts presented.

In terms of participants and recruitment, individuals who took part in the study were self-selecting, and many were self-advocates and therefore likely to be more aware of stigma and its negative consequences. People who feel less able to stand up to stigma, or who are less aware of it, may have been less interested in taking part in such research. In future, there may be worth in recruiting through day centres and mental health services, in order to broaden the range of participants with regard to pre-existing knowledge of intellectual disability stigma, who may report different responses to those given by advocates. By the very nature of being self-advocates, it is likely that these individuals would give a more resisting response than those who are less aware of the stigma directed at their group. However, individuals who are less aware that they are treated more poorly, or differently, than the rest of society are equally as important to hear from. Considering social comparison theory (Dagnan & Sandhu, 1999), it could be hypothesised that if one does not perceive oneself as being treated poorly, one will not see oneself as different. Therefore, one’s sense of self may be protected by lack of stigma awareness, which is the necessary first stage in order for internalisation to take place (Corrigan & Rao, 2012). However, experimental evidence is currently missing from the intellectual disability field to support this hypothesis. When considering the social model of disability

(Shakespeare, 2006), a distinction is made between impairment and disability, in which the constructs of a society disable a group of people, by its approach to their impairment. The discrimination faced by people with intellectual disabilities covers all aspects of life; relationships, parenting, employment, housing, daily activities etc. Therefore, many people with intellectual disabilities lack access to aspects of society which enable positive feedback and wellbeing, as they are often present but not included in their communities (Anderson & Bigby, 2015). Therefore, even if unaware of stigma and being treated differently, the widespread impact of intellectual disability discrimination may well still negatively impact the sense of self of these individuals; who may not be protected by a lack of stigma awareness. Therefore, including people in future research who are less aware of stigma would allow further investigation into stigma models and how these might apply to the intellectual disability population.

A further consideration with regard to participants is that the sample population was over 80% White. Increasing the number of Black, Asian, and minority ethnic participants would also be useful in understanding how the intersection of ethnicity and intellectual disability might play out in responding to stigma.

With regard to the RIDS measure itself, in order for consistency of coding to be ensured across participants, the first emotion, cognition, behaviour, and motivation given were the ones used for coding. Whilst this is a common technique across analysis of narrative data, it makes the assumption that the first thing said is the most relevant, true, or important. This could be managed in future investigations by including a confirmatory question, such as ‘which would you feel most’ or ‘which one do you think you would do?’. There were also a number of responses that were unable to be coded due to ambiguity, particularly in the RIDS-M. Again, this is a common limitation when coding qualitative data but might be addressed in future studies with a possible follow up question such as ‘what would you want to happen next?’ to elicit the outcome participants hope for as an indication of motivation.

Due to the unfortunate need for the COVID-19 study amendments, the study did not have pre- and post-outcome data from the STORM intervention. This would have enabled further analysis of the RIDS as to whether it was sensitive to change. It would also have provided a larger sample size, allowing more concrete conclusions to be drawn regarding statistical analysis. A higher participant number would also allow the opportunity for higher numbers of responses within the lesser-used typologies of each subscale, again adding weight to the analysis outcomes.

Conclusion

Bearing these limitations in mind, it can be concluded that the RIDS appears to be an effective method of eliciting emotional, cognitive, behavioural, and motivational responses to hypothetical stigmatizing scenarios in people with mild to moderate intellectual disabilities. The picture-story task has been well established in other areas of intellectual disability research and also appears to be effective in the stigma field. Anecdotal feedback from participants indicated that the scenarios depicted are true to the real-life experiences of people with intellectual disabilities, adding value to the validity of the new measure. This pilot study indicates that the RIDS is worth further refining and validation, with more robust statistical analysis to compare against other measures of similar constructs.

Further Investigations

Initial findings suggest that the RIDS is worth further investigation. In future studies, as well as removing scenario five and the final two behavioural questions, it may be worth considering an additional question to further elicit the perceived intent of the other. For example ‘why is the other person treating you that way’, if treatment is identified as poor or unfair. This could help elicit further information as to the participants' perception of the cause of the unfair treatment, and whether this is understood as being related to their intellectual disability label or not. However, this would need careful developing and piloting as taking another's perspective can be very difficult for some people with intellectual disabilities.

It is possible that future investigations may elicit additional responses to stigma not seen in the current study, for example, downward social comparison. If so, additional typologies may be added to the RIDS coding frame and allocated an appropriate score in relation to the continuum of responses, from internalising to resisting (Corrigan & Watson, 2002).

Clinical Implications

Following further refinement and testing, the RIDS has the potential to be of use in both clinical and research settings. When considering stigma intervention studies at the individual level, the way in which an individual responds to stigma is a key outcome. If the RIDS is shown to be sensitive to change, it could be used as an outcome measure to assess whether or not participants undertaking an intervention are better able to resist stigmatising attitudes and actions upon completion of such a group. With regard to use in clinical settings, the existing literature indicates that those who internalise stigma are more likely to develop mental health difficulties and make more use of mental health services. Therefore, the RIDS could be used as part of assessing individuals with intellectual disabilities who access mental health services, in order to use as a clinical tool. This could be directly discussed with the individual if aspects of their mental health are related to stigma. For example, with someone presenting with low mood which is influenced by the societal ideas that they are not worth as much as someone without an intellectual disability, or as capable of achieving their goals. It could also help guide intervention and care plans, whilst serving as a useful reminder to clinicians working in this field that the presenting difficulty is often incorrectly located within the individual, and conversations regarding the structures around people with intellectual disabilities could help broaden the narrative about where the ‘problem’ lies.

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Part 3: Critical Appraisal

Introduction

This critical appraisal expands on the points raised in the discussion and limitations, with a particular focus on the difficult balance in this study between quantitative and qualitative epistemologies. Firstly, it will cover why I chose this area of work for my thesis, and also include more information on the impact of the COVID-19 pandemic on the current study. Personal reflections are included throughout.

Why I Chose This Topic

Prior to clinical psychology training at UCL, I worked as an assistant psychologist in community teams for people with intellectual disabilities. I initially found this area of work a little by accident; being placed there as part of my master's degree, I instantly fell in love with this work and knew this was an area I wanted to pursue my career in. I had heard of my supervisors Katrina and Andrew through their writings and conference presentations and was glad to have the chance to work with them on this project. My clinical work had shown me how poorly many people with intellectual disabilities are treated, both directly, and by the systems they belong to. The injustice of this is striking to anyone connected with the intellectual disability population. The idea of combining my passion for supporting people with intellectual disabilities with my academic career was an obvious decision for me and I am glad to have been able to contribute to this area of academic work. I am looking forward to continuing my career as a qualified psychologist in an intellectual disability service and hope to keep the topic of stigma present in my future work.

The Impact of the Pandemic

As noted in the empirical paper, the original design of this study had to be greatly amended in response to the COVID-19 pandemic, following the halt of all face-to-face research nationally. Originally, the new measure development would have been an integrated part of the

STORM feasibility project and would have included pre- and post-outcome data from the intervention groups. Recruitment for the STORM project had started just days before the announcement of the national lockdown in March 2020. In response to the need to pause the STORM project, it was decided that the new measure, now known as the RIDS, could be developed and initially psychometrically tested prior to the re-commencement of STORM. Although initially this appeared a major setback, it was also true that having the measure at a further stage of its development before the intervention groups began could be an advantage to the overall intervention.

Ethical approval was therefore sought to expand the sample population to any adult with a mild to moderate intellectual disability, with data collection moved to online. This raised a number of potential ethical issues to be considered and carefully planned for to avoid any undue harm or distress. This included the potential elicitation of painful emotions during a videocall, where distress may be more difficult to notice, communicate, and manage. In initial communications, the ethics board were concerned that people with intellectual disabilities may be less able than the general population to manage such emotional distress and requested that a supporter be present throughout their participation in this project, including completing the measures. However, this assumption in itself could be considered somewhat discriminatory and so I advocated with the committee that this level of supervision appeared unnecessarily stringent and threatened participant choice. As an alternative, I contended that participants should be offered an explicit choice of whether they wanted someone to be present for the initial meeting and for a debrief following the measures, but that this should not be enforced as a blanket rule. As well as maintaining participant choice, this felt important to advocate for, as many people with intellectual disabilities live alone with low-level support, or may not have a supporter they felt comfortable sharing this information in front of. This perspective was communicated to the ethics board, who subsequently approved the less stringent supervision of individuals participating in the study, as seen in Appendices K and L. As a part of these less-stringent measures, the name of a trusted supporter was taken before each participant engaged in the tasks, in case of heightened levels of distress. However, none of the 30 participants in the current study required their named supporter to be contacted. A handful of participants reported feeling anxious in response to specific scenarios which reminded them of an incident they had experienced themselves in the past. These incidents were managed during the study by offering participants a break, reminding them they could stop at any time, and that the supporter could be contacted if needed. As previously noted, none of the participants ended their participation early, or required their supporter to be contacted, and were able to manage this anxiety independently. Of note, many participants reported anecdotally that they enjoyed the task, even when acknowledging the unkind and sensitive nature of the topic, as they were glad to be a part of research that might help people with intellectual disabilities more generally.

Experts by Experience

An important part of this project was to ensure it was informed by people with intellectual disabilities as much as possible. The STORM Expert Advisor Group and Mencap Research Forum were both instrumental in creating the scenarios within the RIDS including the wording, photographs, and relevance of the stigma they depicted. Including people with intellectual disabilities in the research conducted about them is essential in practicing what we preach and not falling into stigmatized views ourselves as researchers. As Gjertsen (2019) notes, it may be more time consuming for the researcher, but the benefits far outweigh the costs. We need to accept and appreciate the unique perspective experts by experience can give and take the time to ensure these are held with the same value as academic experts.

This issue was raised by a self-advocate on social media, during the recruitment phase of the project. She was unhappy with the idea that research about people with intellectual disabilities should be conducted by a person without an intellectual disability at all and did not agree that expert consultation went far enough on the topic of inclusion. She also disagreed with the idea that such research should be carried out with funding given to universities, as opposed to intellectual disability services themselves. This was difficult to hear, as her opinion jarred with both my personal values and hopes for the project, as well as those of the wider research team. However, her views were important to hear, given that she belongs to this marginalised group, and I do not. There may not be a clear answer to this difference of opinion, but a helpful balance of research by 'academics' compared with people with intellectual disabilities themselves could be to have a co-researcher with an intellectual disability in future research regarding the RIDS.

Recruitment

Recruitment was designed using volunteer and snowball sampling, by contacting organisations that run groups for people with intellectual disabilities and also sharing the recruitment advert on social media platforms that were likely to be seen by potential participants. For example, Learning Disability England shared the advert in their online newsletter. Whilst this was a helpful way to reach a greater number of people from all over the country, this resulted in many of the participants belonging to self-advocacy groups. As such, many were very aware of the unfair treatment people with intellectual disabilities are subject too, and this was a very important matter for many participants. Whilst it is hopeful to see and hear from so many people who were passionate about the subject, these self-selecting individuals may not wholly represent the responses to stigma of the wider intellectual disability population. It is likely that some people are unaware that they are treated poorly, and that others lack the confidence to talk about this emotive topic. However, these voices play a vital role in understanding how stigma impacts people differently, and the variety of responses to it. This poses a difficult methodological question; how do we hear from people who may be harder to access and less willing and able to share their views and experiences in research? Recruiting people with disabilities into health research is a well-known challenge in this field and some noted barriers include the structure and accessibility of research, scepticism among people with disabilities, power differentials, the inaccessibility of academic text, and gatekeepers who are over-burdened and disinterested (Banas et al., 2019). These authors go on to name a number of solutions for the noted challenges, many of which were present in this study, such as educating regulatory bodies, making information and consent accessible, attending to cognitive barriers, and providing support during data collection. Banas et al. (2019) also suggest making findings accessible, which will be achieved with the results of the current study, as an Easy Read report will be sent to all participants with information on the findings. Future recruitment may be improved in order to reach unheard voices by forming relationships and trust with more intellectual disability groups, increasing contact with gatekeepers to improve scepticism, employing a co-researcher with an intellectual disability, and continuing to address and attempt to level power differentials (Banas et a., 2019).

Measure Development

With regard to developing the RIDS, there were a number of important decisions to be made regarding how the data would be analysed and interpreted. This quote from Boateng et al. (2018, p.1) nicely reflects my experience of this process "As science advances and novel research questions are put forth, new scales become necessary. Scale development is not, however, an obvious or a straightforward endeavour." This being an explanatory study, the exact method of analysis was not clear from the outset, given that the procedure was designed bottom-up and analysis would depend on the format of the data derived during the RIDS interviews. Coding the data using content analysis, it was important to stay with the words people used in their responses, and not to over-interpret or imply meaning to their responses, based on pre-existing knowledge of stigma theory. Content analysis sits halfway between quantitative and qualitative epistemology and regular meetings were helpful in ensuring that additional meaning was not inferred on the phrases used by participants. This was difficult at times, given that some people with intellectual disabilities may use certain phrases or words in a different way to the general population, or have a more limited vocabulary to describe a range of different emotional experiences they may be having. However, in order for replicability and scientific rigour, this was an important part of the analysis process. Another difficult aspect of the study in terms of balancing quantitative and qualitative epistemologies and values, was the process of grouping the category typologies into broader codes. On one hand, this loses the nuance of narrative responses, by grouping certain responses together and reducing down the amount of variation. On the other hand, without such grouping, the data remain dispersed and individualised and fewer conclusions can be drawn from the results.

Following the categorical coding, these codes were required to be transformed into numerical scores, so that further analysis could take place and comparison with existing measures. Again, this posed a difficultly in balancing epistemologies between bottom-up versus top-down approaches. While the coding had been based closely on the narrative data itself, allocating these codes a numeric score needed informing by theory, in order to better understand the response types. Whilst there have been numerous studies investigating mental illness stigma, and there is evidence to suggest that relevant theory broadly this fits the intellectual disability population, this is not a certainty. Therefore, there is a possibility that the scoring frame, based on wider stigma theory, may not be wholly applicable to intellectual disability stigma. However, in lieu of an alternative theory, this was the most appropriate and evidenced based option at this time. The scoring frame and its use of negative and positive scores may also be useful in the next stage of the RIDS development. As the STORM intervention re-starts, there will be the opportunity to assess pre- and post-outcome data and analyse whether the RIDS is sensitive to change. Although I feel disappointed that this was not available in the current study as initially intended, I am glad that the STORM research team will be able to continue this work and am hopeful that the RIDS can be of use in this important intervention study.

Participant Experiences of Stigma

When devising the RIDS items including the type of stigma, wording, and supporting photographs, the most important aspect was that the scenarios devised were relevant and applicable to the everyday lives of people with intellectual disabilities. Whilst from an academic and research perspective, the feedback from participants that this was the case was reassuring and I felt glad that the RIDS was accurately representing true to life situations. However, from a human rather than academic perspective, I also felt very sad to hear from multiple participants that they recognised these scenarios and had to repeatedly put up with them in everyday life. For example, comments such as “I get this all the time”, “unfortunately, that's just the way society is”, “not surprised because it happens to me all the time”, “I've had that done to me in hospital, they talk over you and instead of talking directly to the person, the patient, they talk over and I think that is really rude”, “When they don't include you, that’s it, that does knock you down I tell ya” put into perspective the reality of how pervasive these encounters can be for some people. However, there was also a lot of hope from participants that things can improve for them and other people with intellectual disabilities, and many expressed how happy they were to be a part of such research, some enquiring about other projects they might take part in to help raise awareness of this topic. Their responses indicated that despite continuing stigma, people with intellectual disabilities can show real resilience in the face of discrimination and remain hopeful that things can improve.

Unexpected Findings

As noted, the current study was susceptible to recruiting individuals who were self-advocates with heightened awareness of the anti-stigma movement. This may help explain why the study did not identify any deflecting or downward social comparison responses. Logic dictates that those who are part of a self-advocacy group would oppose intellectual disability stigma for all group members, not just in its application to themselves.

The lack of correlations between the RIDS, wellbeing, and self-esteem were unexpected. However, given the early stages of the current study, may not be surprising. Whilst it is too early to draw a firm conclusion on this, there are several theoretical ideas which may explain why resisting and internalising responses both are associated with high and low levels of wellbeing and self-esteem. On one hand, perception of stigma alone appears to be enough to damage self-esteem in some cases, as well as managing the real-life implications of discrimination. Alternatively, being a part of a minority group can be protective of psychological wellbeing (Branscombe et al., 1999) and being able to differentiate one's sense of self from discriminatory views, no matter how pervasive these may be, can mediate the impact of the prejudice within broader society (Jahoda et al., 1988). Whilst there is evidence for all these pathways, continued research into mediating factors is warranted, as is the importance of assessing the impact of stigma at the individual level to avoid making assumptions about how a person might appear to be affected.

Conclusions

In summary, this study has shown that the picture-story method is effective in eliciting responses to hypothetical scenarios of intellectual disability stigma in the new RIDS tool. It is the first measure to directly assess the internalisation and resistance of public intellectual disability stigma, which has significant implications for furthering understanding of how discrimination can impact an individual's sense of self. This has implications for supporting the wellbeing of the wider intellectual disability community, as well as those accessing support for their mental health, given the relationship between experiences of stigma and mental health difficulties. This initial exploratory study has identified a range of responses enacted by people with intellectual disabilities in the face of stigma indicating that the RIDS warrants further investigation and refinement.

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Appendices

Appendix A: Recruitment Advert

UCLUS
UCL Unit for Stigma Research

UCL

Opportunity for adults with learning disabilities to take part in research

People with learning disabilities are sometimes treated unfairly by other people.

We want to find out how people with learning disabilities deal with being treated unfairly.

This research will give you a chance to have your say in how you would respond to unfair treatment.

Would you like to take part in this research?

Due to COVID-19 we are doing this research online. You will need an email address, access to wifi, and a computer or smartphone to take part.

Who are we?

This research is being done by the UCL Unit for Stigma Research (UCLUS). If you would like to get involved or know someone who would, please contact Abigail Goldsmith-Sumner:

Email: abigail.goldsmith-sumner.18@ucl.ac.uk

Twitter: @AbigailSumner2

Photo credits: www.photosymbols.com

Appendix B: Easy Read Information Sheet

Research Information Sheet

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

Research means finding out about things.

We are the research team

Abi

Michaela

Our team is from University College London.

You can contact Abi to talk about this research.

Abigail.goldsmith-sumner.18@ucl.ac.uk

Why we are doing this research

We want to find out what people with learning disabilities think and do when they are treated unfairly by others.

We have made a new questionnaire to find this out.

We want some people to help us try out the new questionnaire by answering the questions. This will help us know if the questionnaire is working.

We are asking you to take part

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

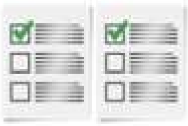
You can talk about it with other people like your family and friends if you want.

What happens if you take part?

2

If you take part, you will meet with a researcher 2 times.

Time 1 they will explain the research and you can ask questions.



Time 2 you will complete the new questionnaire, plus two other ones we already have finished.

These 2 meetings will be on a video call. This means you will see the researcher on video on a computer or phone. You will not be together in the same room.

We can send you Easy Read information on how to use the videocall.

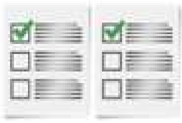
In the 2nd meeting you will listen to some short stories and look at some photographs in the new questionnaire.

Some stories are about being treated fairly and some are about being treated unfairly.

You will imagine you are the main person in the stories.

You will answer questions about the stories.

Your answers will be recorded for us to listen to later. This helps us know if the questionnaire is working.



You will also answer two more questionnaires which ask about how you have been feeling.

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** now. You can say no later on if you change your mind.

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.

Changing your decision

You can stop taking part in the research at any time.
You don’t have to tell us why.

What we do with your information

Your answers to questions the researcher asks will be confidential. That means I don’t share your answers with anyone you know.

If you tell me something that makes me worry about your or someone else’s safety, I may need to tell someone. This is to keep you and others safe.

Only the research team at UCL will listen to the recording of you saying your answers.

Where we keep your recorded answers

We will keep the recording of you saying your answers in a locked place on a computer.

The computer will use passwords to keep your answers safe.

Your name will not be stored with your conversation.

Good things about taking part

What we find out may help you and other people with learning disabilities.

✓ Your answers will help us make sure the questionnaire is working

We will give you information to help you stand up for yourself if treated unfairly.

It might feel good to talk about the way you are treated by other people. The researchers will listen and support you.

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.

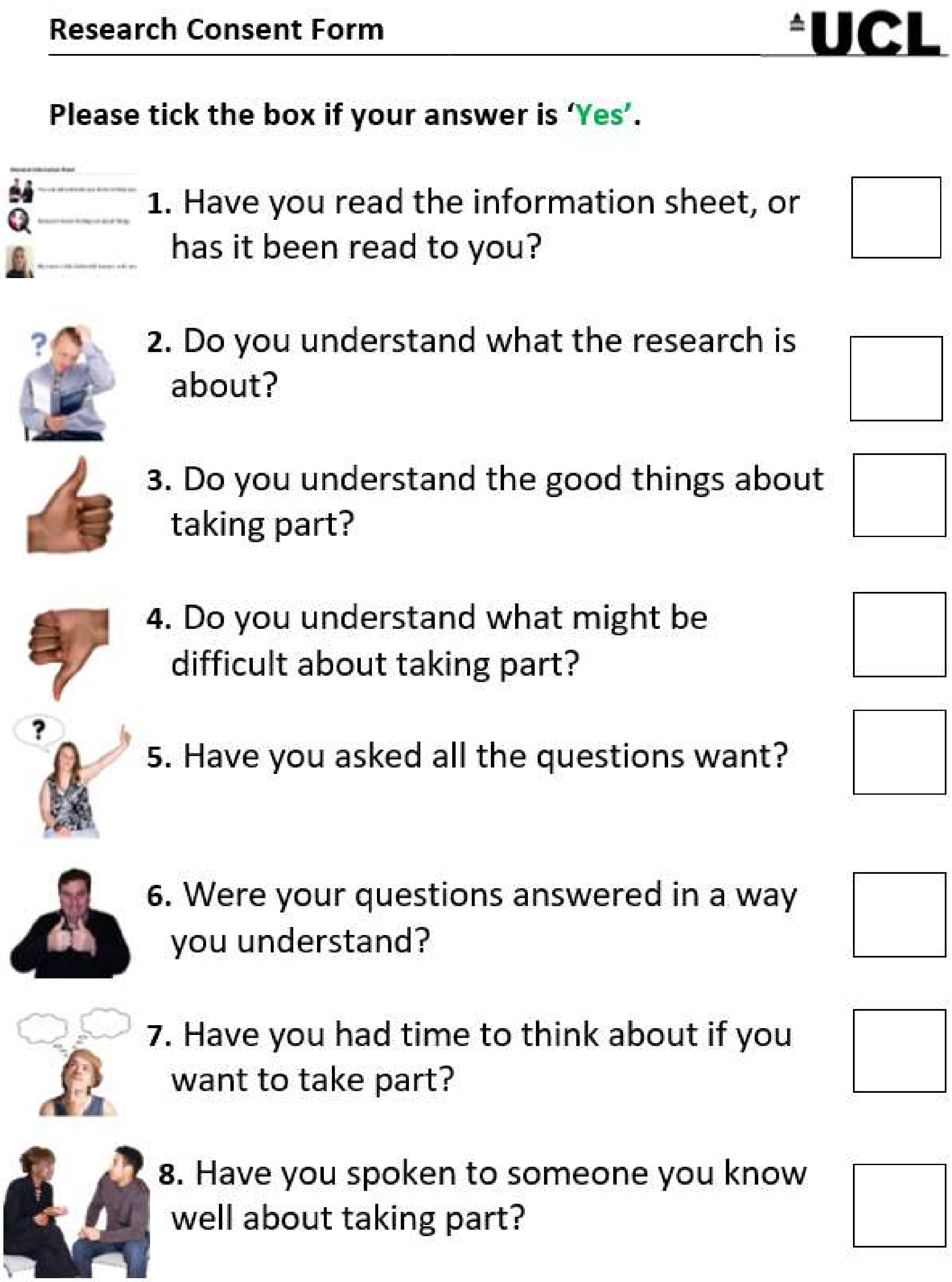
How to make a complaint

If there is a problem, you can talk to someone from the research team.

Abi's contact details are on page 1.

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

Appendix C: Consent Form



Research Consent Form

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

1. Have you read the information sheet, or has it been read to you? ☐
2. Do you understand what the research 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 want? ☐
6. Were your questions answered in a way you understand? ☐
7. Have you had time to think about if you want to take part? ☐
8. Have you spoken to someone you know well about taking part? ☐

9. Do you understand that the meetings will be on video call and not face to face? ☐

10. Do you understand that your answers to questions about you and how you feel will be recorded? ☐

11. Do you understand what confidential means and that all your information will be kept confidential? ☐

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

13. 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.

Researcher's initials:_________ Signature: __________________________ Date: _________

Appendix D: The RIDS

Responding to Intellectual Disability Stigma (RIDS)

Information for Interviewers

The RIDS is an interview assessment of how people with intellectual disabilities react emotionally, cognitively, and behaviourally in situations where they are treated unfairly by people without intellectual disabilities.

The interview includes 6 stories of everyday situations people with ID often find themselves in. Some are positive situations where they are treated fairly, and some are negative situations, where they are treated with prejudice and stigma. The person is required to imagine themselves in each story and answer questions about how they would respond.

This method may elicit difficult emotions in the person taking part. As such, in the first meeting, you should ask the interviewee to identify a supporter who may require contacting at a later point. If requested by the interviewee, the supporter may be provided with an information sheet and consent form to understand the interview.

The interview must be recorded on an encrypted Dictaphone as well as a videoconferencing platform (if not conducted face to face) for later coding.

The interview is intended to have a conversational style and you may repeat the contents of the story as necessary for it to be understood. However, do not change the content of the story.

Each story has two supporting photographs. You must show the corresponding photograph when prompted in the interview schedule to the person you are interviewing.

Story 1 requires some information to be gathered before it can begin. Replace the X in the story with the name of the person who the individual with ID would or might take with them to the doctor for support.

After each story, go through the list of questions using the prompts as required. Allow the interviewee to give as much information as possible but move on if the answer deviates from the original question. Complete all 6 questions before moving on to the next story and set of questions. Continue until you get to the end of story 6.

At the end of the questions, ask the interviewee about a happy or exciting event which has happened to them recently and ask questions about the detail of what happened. This is to help reduce the chance that interviewees will leave the interview ruminating on social injustices. Remind them that the stories were made up and thank them for taking part. Make a final assessment of their mood before the session has ended and provide emotional support if necessary. It may also be appropriate to ask them to contact the supporter they initially identified. Signposting to further support available may also be required, and the participant must be provided with the information of resources regarding standing up to stigma.

Explanation to be read to participants

A lot of different things happen in life. I want to find out what you think and feel when different things happen. So, I am going to tell you some short stories. I want you to imagine you are the main person in the stories. Then I will ask you some questions.

There are no right and wrong answers. You are the expert here. I'm just really interested in your point of view.

If you do not want to talk about one of the stories, that's fine, just tell me. It is your choice. You can end this conversation whenever you want.

Story 1

This story is about going to the doctor. Do you ever take anyone with you when you go to the doctor? Who?

P: If it was something more complicated, who would you take?

P: If you did want to take someone with you for support, who would you take?

You go to the doctor with X. (Photo 1a) You get called into the doctor's room. The doctor asks you and X to sit down. (Photo 1b) He looks at X and asks her/him why you are there. X tells the doctor why you are there. All the time the doctor only talks to X and doesn't talk to you.

Story 2

This story is about going to college.

(Photo 2a) You are at a college course.(Photo 2b) You are having a cup of tea with some friends in the café at lunchtime. They start talking about looking for jobs. You tell them that you would like a job too. One of them says "*you'll* never get a job".

Story 3

This story is about going on the bus.

(Photo 3a) You are going somewhere new on the bus. You are not sure of the route. You worry that you are on the wrong bus. (Photo 3b) You ask the driver for help. At the next stop, the driver calmly and slowly explains the route. He smiles and checks that you understand where you need to go.

Story 4

This story is about a day out with your friend.

(Photo 4a) You have had a nice day out with your friend. You are walking home together (Photo 4b). A teenager walks past you. You have never seen him before. He stops and calls you nasty names.

Story 5

This story is about going shopping.

(photo 5a) You are out shopping. You use your last £5 to buy a beer and a magazine. (Photo 5b) The shop keeper looks at your wallet/ purse with no money in it. He looks at you. He says, “are you sure you’re allowed that?”.

Story 6

This story is about volunteering.

(Photo 6a.) You are spending the day at a new volunteering placement at a charity shop. You overhear the other people who work there organising a meal out that night. (Photo 6b.) You realise that you are the only one not invited.

Follow-up Questions

Q1. How are you feeling when you are the only one not invited to the meal?

Q2. How do you think the people are treating you when you are not invited to the meal?

Q3. What would you do when you realise you had not been invited to the meal?

Q4. Why would you do that?

Q5. What would the next step be?

Q6. What would you do next time?

RIDS Supporting Photographs

1a.

1b.

2a.

2b.

3a.

3b.

4a.

4b.

5a.


TOBACCO
THE AGE OF
ASK FOR A SPECIAL EDITION
MORE SCRATCHCARD WINNERS THAN EVER
ChapStick
Telegraph
HOSPITAL SNOOPS SACKED

5b.


supporting patients
improving spaces
giving massage therapy
providing advice and information
funding specialist equipment
volunteers i
Donate to our shops

6a.

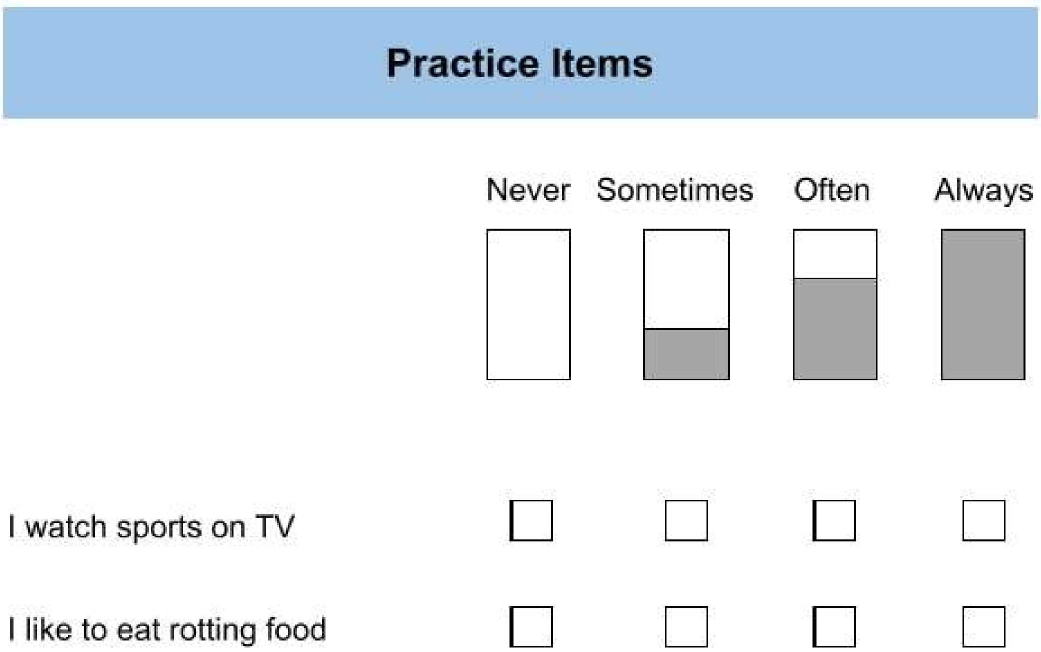
6b.

Appendix E: Rosenberg Self-Esteem Scale (RSES)

In general

	Never	Sometimes	Often	Always
I feel I am a good person, as good as others	☐	☐	☐	☐
I feel I have a lot of good qualities	☐	☐	☐	☐
I am able to do things as well as most other people	☐	☐	☐	☐
I feel I haven't done anything worthwhile	☐	☐	☐	☐
I like myself	☐	☐	☐	☐
At times I think I am no good at all	☐	☐	☐	☐

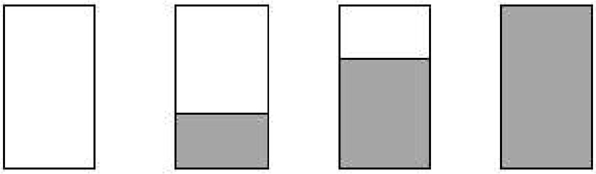
Appendix F: Warwick-Edinburgh Mental Wellbeing Scale-ID (WEMWBS-ID)



Practice Items

	Never	Sometimes	Often	Always
I watch sports on TV	☐	☐	☐	☐
I like to eat rotting food	☐	☐	☐	☐

Over the last week

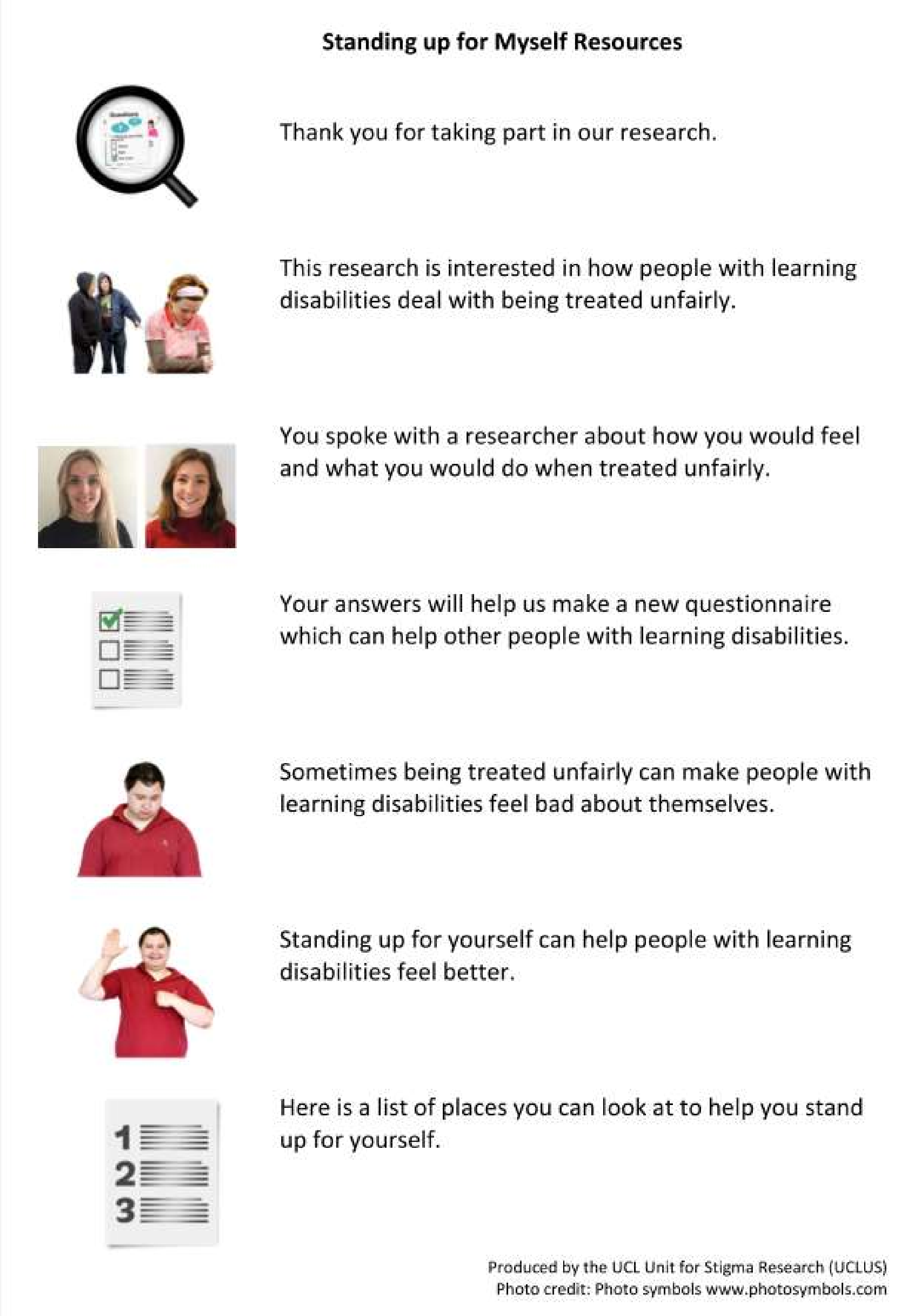


	Never	Sometimes	Often	Always
I felt hopeful about the future	☐	☐	☐	☐
I felt useful	☐	☐	☐	☐
I felt relaxed	☐	☐	☐	☐
I felt interested in other people	☐	☐	☐	☐
I had lots of energy	☐	☐	☐	☐
I dealt with problems well	☐	☐	☐	☐
I thought clearly	☐	☐	☐	☐

Over the last week

	Never	Sometimes	Often	Always
I felt good about myself	☐	☐	☐	☐
I felt close to other people	☐	☐	☐	☐
I felt confident	☐	☐	☐	☐
I felt able to make my own decisions	☐	☐	☐	☐
I felt loved	☐	☐	☐	☐
I was interested in new things	☐	☐	☐	☐
I felt cheerful	☐	☐	☐	☐

Appendix G: Standing Up For Myself Resources



Standing up for Myself Resources

Thank you for taking part in our research.

This research is interested in how people with learning disabilities deal with being treated unfairly.

You spoke with a researcher about how you would feel and what you would do when treated unfairly.

Your answers will help us make a new questionnaire which can help other people with learning disabilities.

Sometimes being treated unfairly can make people with learning disabilities feel bad about themselves.

Standing up for yourself can help people with learning disabilities feel better.

Here is a list of places you can look at to help you stand up for yourself.

Produced by the UCL Unit for Stigma Research (UCLUS)
Photo credit: Photo symbols www.photosymbols.com

Mencap Young Ambassadors talk about how other people see learning disabilities.

They also talk about what they are proud of.
https://www.youtube.com/watch?v=N5I877T7RZs

Thomas and Lauren talk about their work as young ambassadors for Mencap.

https://www.youtube.com/watch?v=WlvTEjqS-Ck

People talk about what a learning disability is and what it means to them.

https://www.youtube.com/watch?v=tfkVA2BKIyY

This website has information on how to show you are proud of having a learning disability

http://learningdisabilitypride.org.uk/

Jodie talks about her experiences of stigma and how she stands up for herself. The video also talks about a big group called Self-Advocates Together.

https://www.youtube.com/watch?v=QUuODjxcOlQ

https://selfadvocacyuk.wordpress.com/

Alison talks about her experience of stigma and what she does to keep herself coping well.

https://www.youtube.com/watch?v=bSjTwk07TXY&feature=emb_logo

Robert and Tom are included in their community by delivering a paper round.

https://www.youtube.com/watch?v=pRvZyyb0H8k

These videos show the other parts of life that people with learning disabilities are proud of.

https://www.eastsussex.gov.uk/socialcare/disability/learning-disability/learning-disability-partnership-board/involvement-matters-team/theres-more-to-me-than-ld/

WE ARE INDIVIDUALS
NOT DISABILITIES

Young people talk about the changes they want for people with disabilities.

https://www.youtube.com/watch?time_continue=281&v=x7lN-YxgiEM&feature=emb_logo

If you feel very sad or worried about being treated unfairly, you can talk to your GP. They can give you more advice about services in your area.

Here are other services that can offer support:

SANE runs a mental health helpline from 4:30pm to 10:30pm daily (0300 304 7000)

RESPOND
from hurting to healing

Respond is a charity that supports people with learning disabilities who have experienced negative experiences or trauma.

Link to website: http://respond.org.uk/who-we-are/contact/

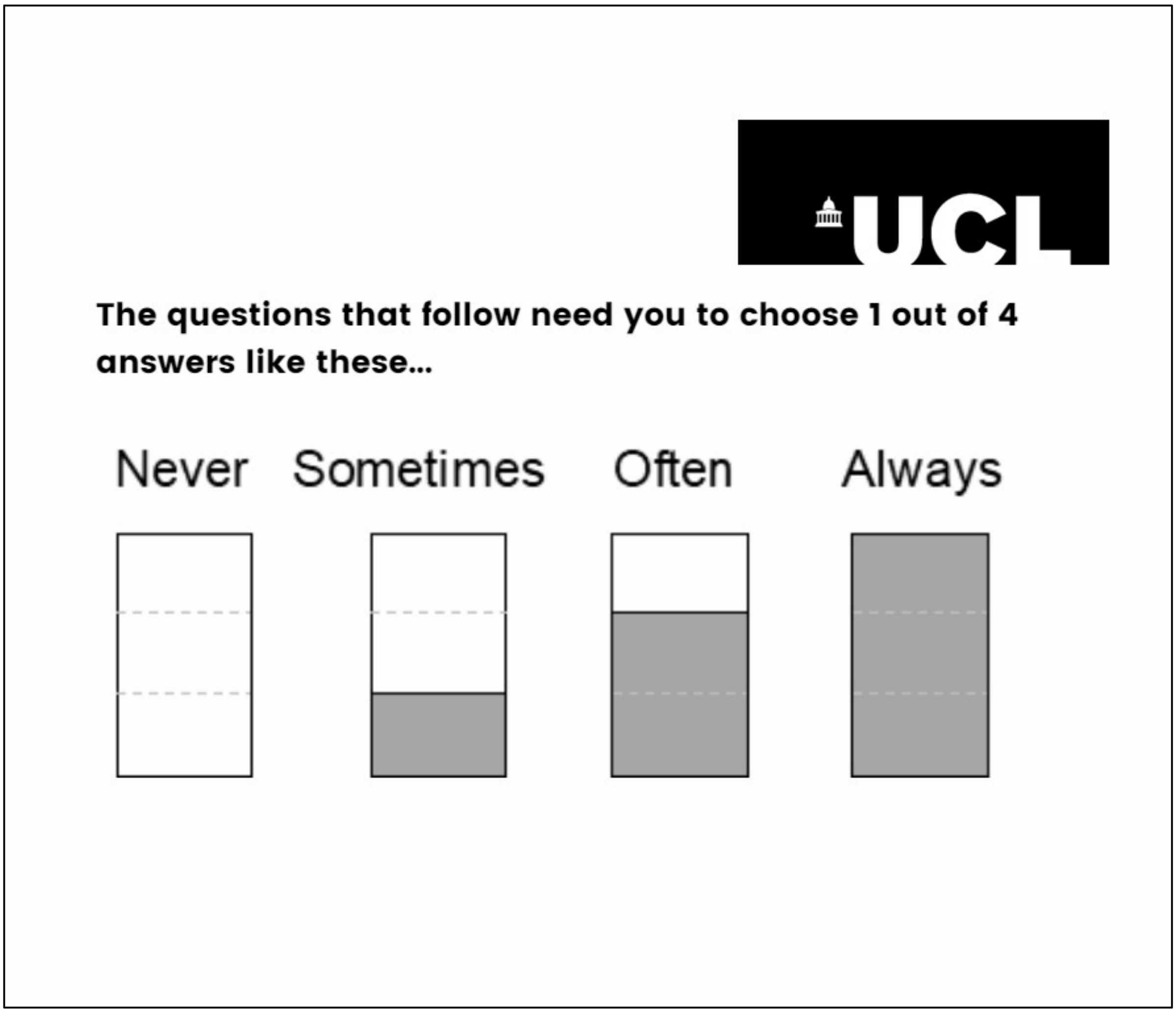
VS VICTIM SUPPORT

Victim Support is a charity that you can call if you have been a victim of crime. Call for free on 0808 1689 111

Link to website: https://www.victimsupport.org.uk/help-and-support/get-help

Produced by the UCL Unit for Stigma Research (UCLUS)
Photo credit: Photo symbols www.photosymbols.com

Appendix H: Likert Scale Visual Response Aid



The questions that follow need you to choose 1 out of 4 answers like these...

Never Sometimes Often Always

Appendix I: Ethics Amendment

1 **Project ID Number: 0241/005**

Name and e-mail address of Principal Investigator: Dr Katrina Scior
K.scior@ucl.ac.uk

2 **Project Title:** The STanding up fOR Myself (STORM) psychosocial group intervention for young people and adults with intellectual disabilities: Feasibility Study

3 **Type of Amendment/s (tick as appropriate)**

Research procedure/protocol (including research instruments) ☒
Participant group ☒
Sponsorship/collaborators
Extension to approval needed
Information Sheet/s ☒
Consent form/s ☒

4 **Justification** (give the reasons why the amendment/s are needed):

1. As part of this study, we are assessing how to assess a range of health related and social outcomes with people with intellectual disabilities (ID). For one key outcome, stigma resistance, there is no measure validated for use with people with ID. An amendment is sought to pilot a new stigma resistance measure that we have developed with input from people with ID. This new tool was designed to assess how people with ID might respond in a range of hypothetical, potentially stigmatizing situations.
2. Our plan to develop this new tool was included in the original ethics application - the new tool has now been developed and is ready for piloting.
3. Due to Covid-19, data collection for the main study has been temporarily suspended, as this as per study protocol is face to face and the third party groups it is focused on have temporarily stopped meeting. Piloting of the new stigma resistance measure using non-face to face methods will allow us to refine the tool so that it ready for use in the main study once this resumes. It will also allow us to validate the new tool against existing measures of self-esteem and well-being, which have been associated with stigma resistance in the existing literature.
4. We are proposing to begin piloting the new tool with research participants who are not involved in the main STORM study, using digital means of data collection. They will be recruited in partnership with the same third sector organisations as set out in the original ethics application (e.g. Mencap, People First Dorset), but their participation would not be contingent on them being members of an existing group that agrees to take part in the main STORM study.
5. As the development and piloting of this new tool is the main focus of a doctoral thesis project due for submission in June 2021, we are keen to avoid delays.
6. A new Information Sheet and Consent Form have been produced, specific to the pilot of the new tool (please see appendix B and C).

5 **Details of Amendments** (provide full details of each amendment requested, state where the changes have been made and attach all amended and new documentation)

Research Procedure

The new assessment tool, the Responding to Intellectual Disability Stigma tool (RIDS; see Appendix A), will be piloted using an online video conferencing platform. Participants will be asked which platform they are familiar with, for example Teams, Skype, Zoom. Due to the lockdown, many people with ID have already become familiar with Zoom and there is Easy Read information available on how to access and use it (see appendix D). This will be sent to potential participants before the first meeting if this is the platform they choose. The researcher will provide information about the study, obtain consent and complete data collection via video call. The RIDS involves presenting scenarios to participants verbally alongside corresponding photographs, which will be done via the share screen function. Participants will also see and speak with the researcher whilst being able to see the photos presented as part of the tool. Information about the study will be circulated via third sector organisations and also social media outlets of the UCL Unit for Stigma Research (UCLUS) and its researchers. Any potential participants will be invited to an initial conversation via video call about the study – they will have the choice of being supported e.g. by a family member, support worker or friend for this initial meeting. If they indicate at the end of this meeting that they are happy to take part, a second meeting will be arranged Potential participants will be given at least 24 hours to consider the information and consult with trusted others before deciding if they would like to take part in the pilot. During the second meeting formal consent will be obtained, possibly in the presence of the identified supporter if that is what the participant would find helpful, and the new tool completed alone. In addition, the following measures included in the original ethics application: Warwick Edinburgh Mental Wellbeing scale (WEMWBS), Rosenberg Self-Esteem (RSE) scale, and sociodemographic information will be collected. The WEMWBS and RSE will also involve presenting corresponding pictures via video call screen share during data collection. At the end of the meeting participants will be given a debriefing, which will include the researcher checking their wellbeing and potential need for any further support to discuss the research and their concerns.

Statistical analysis will be conducted to assess the correlation between RIDS, WEMWBS and RSE scores, and the effect of participant socio-demographics.

Participants' verbal responses will be recorded with their consent via the video call platform used and also as a back-up, an encrypted Dictaphone to be stored confidentially and securely before being transcribed via Trint software. After transcription, the video call and Dictaphone recordings will be destroyed.

A revised information sheet and consent form are included in Appendices B and C.

6

Ethical Considerations (insert details of any ethical issues raised by the proposed amendment/s)

1. The RIDS tool involves exposing participants to potentially upsetting hypothetical situations of being exposed to stigmatizing treatment, some of which they may have encountered themselves in the past. In addition, the WEMWBS and RSE ask some sensitive questions. Participants will be informed about the potentially upsetting nature of taking part through the information sheet and their understanding of this will be checked during the consent process. Participants will be informed and reminded that they do not have to answer all questions, and that they can withdraw at any time. The initial conversation will include discussion regarding how each participant would let the researcher know if they wanted to pause or stop the interview, to ensure that participants feel able and empowered to make their wishes known and to ensure that the researcher is sensitive to participant's needs and wishes.
   Data collection will be done by researchers who are fully trained and experienced in discussing sensitive topics and who are able to monitor for signs of distress and respond appropriately. After completing the measures, participants will have an opportunity to discuss with the researcher any difficult emotions they may be experiencing. The participant will be asked if they would like to make contact with the supporter identified at the first meeting for discussion and support as needed. The researcher will ascertain whether there is a need for any further support to discuss concerns participants may have and with the participant's consent, wherever possible, will arrange for such support to be offered, e.g. by contacting a relative or other supporter of the person with ID. Data collection meetings will end talking about something positive which has happened to participants recently or upcoming plans, so that they do not leave ruminating on social injustices. They will also be provided with information about services and resources for people with ID that are empowering and can support them in developing or maintaining a positive sense of self in the face of stigma.

2. Assessing capacity and informed consent: Potential participants will be given 24 hours to consider joining the pilot and have the opportunity to ask any questions of the researcher. They will be provided with all the relevant study information in an information sheet and consent form. Given that the video call platform

may be unfamiliar to potential participants and there may be technical issues in using it, potential participants will be given the option of inviting a supporter to join them for the initial meeting. If the individual wishes to be supported, the supporter will also be asked to be available for the first and last part of the second meeting, in order to support the participant. In place of a signed consent form, participants will be asked to give consent verbally and this will be recorded on Zoom and encrypted Dictaphone stating their name and giving consent. This will be stored securely.

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

The voices of people with ID are often missing in research conducted on, for, and about them. Our consultations with expert advisors with ID so far have supported the idea of being asked directly about their experiences, both positive and negative. Although this has the possibility of eliciting difficult emotions, it allows people with ID to share their stories of stigma and help contribute to advancing understanding of their experiences and potential threats to their wellbeing. By avoiding asking about these topics, we are inadvertently contributing to the stigmatizing idea that people with ID are not capable of talking about their experiences or managing their emotions. As our expert advisers with ID have stressed again and again, the opportunity to share can allow people with ID to feel heard and respected and can in itself be seen as a form of self-advocacy which has been shown to be a protective factor against the experience of stigma.

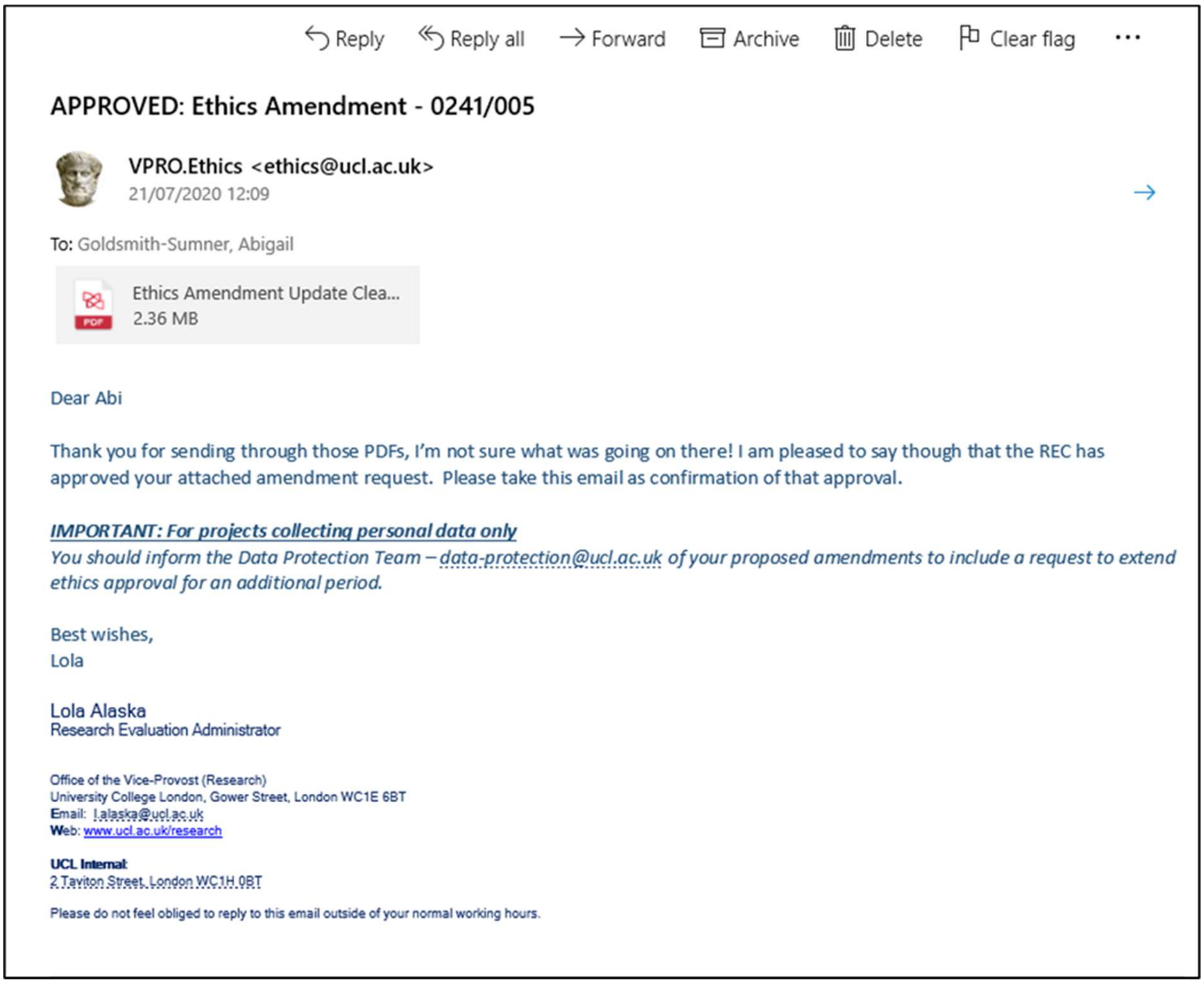
Declaration (to be signed by the Principal Researcher)

- 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.

Signature: [redacted] ……………………………..

Date: ……20.6.2020…………

Appendix J: Ethics Amendment Approval



APPROVED: Ethics Amendment - 0241/005

VPRO.Ethics <ethics@ucl.ac.uk>
21/07/2020 12:09

To: Goldsmith-Sumner, Abigail

Ethics Amendment Update Clea...
2.36 MB

Dear Abi

Thank you for sending through those PDFs, I'm not sure what was going on there! I am pleased to say though that the REC has approved your attached amendment request. Please take this email as confirmation of that approval.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection Team – data-protection@ucl.ac.uk of your proposed amendments to include a request to extend ethics approval for an additional period.

Best wishes,
Lola

Lola Alaska
Research Evaluation Administrator

Office of the Vice-Provost (Research)
University College London, Gower Street, London WC1E 6BT
Email: l.alaska@ucl.ac.uk
Web: www.ucl.ac.uk/research

UCL Internal:
2 Taviton Street, London WC1H 0BT

Please do not feel obliged to reply to this email outside of your normal working hours.

Appendix K: RIDS Typologies Identified Per Scenario

Scenario 1 Typologies - Denial of Autonomy			
Feelings	**Thoughts**	**Behaviours**	**Motivation**
Content Good/ alright/ fine	*Unfair* Treatment is bad/ wrong/ unfair/ rude/ not right/ disrespectful/ unprofessional	*Speak Up* Tell him to speak to me, I am the patient	*Assert* It's the right thing to do/ So that he talks to me/ I have the information
Fearful Worried	*Fair* Treatment is fair/ good	*Leave* Not go back	*Maintain Status Quo* Not confrontive/ don't know how to approach it/ no point
Angry Angry/ annoyed/ frustrated/ insulted	*Questioning* Why am I being ignored?	*Nothing* Unsure/ nothing/ wait/ stay quiet/ leave it/ talk to someone later	*Support* Get it off my chest/ calm down/ feel better/ seeking emotional support
Sad Unhappy/ hurt/ sad/ down/ insecure	*Assertive* He should be talking to me/ preferred treatment	*Complain* Stay quiet and make a complaint later	

Scenario 2 Typologies - Denial of Capability			
Feelings	**Thoughts**	**Behaviours**	**Motivation**
Sad Sad, upset, unhappy	*Unfair* Not nice/ disrespectful/ bad friend/ bullying	*Speak Up* In the moment/ Tell them to stop/ they're wrong/ a bad friend	*Assert* Show what I can do/assert rights/ assert capabilities
Angry Grumpy, angry, frustrated, annoyed	*Fair* Treatment is fair	*Leave* Walk away/ Not go back/ stop being friends	*Punishment* Get them into trouble
	Assertive Asserting rights/ capabilities/ focus on what they can do	*Complain* To tutor	*Maintain Status Quo* Not confrontive/ don't want to argue
		Prove them wrong Go and get a job	

Scenario 4 Typologies - Verbal Abuse

Feelings	Thoughts	Behaviours	Motivation
Angry Angry, annoyed	*Unfair* Not nice/ disrespectful/ bullying/ mean	*Speak Up* In the moment/ Tell him to stop	*Educate* Change the way he behaves
Sad Sad, upset, unhappy, down	*Planning* Plan of action/ what can I do next?	*Ignore* Walk away/ ignore/ do nothing/ just keep going	*Punish* Get him in trouble
Fearful Scared, panic, afraid	*Denigrating* Negative thoughts about the boy	*Report* To police or supporters	*Avoid Escalation* Action could cause an escalation, avoid the situation.
		Escape Run away/ get out as quickly as possible	*Support* Emotional or practical advice

Scenario 6 Typologies - Social Exclusion

Feelings	Thoughts	Behaviours	Motivation
Content Fine/ don't care	*Unfair* Treatment is bad/ wrong/ unfair/ rude/ rejecting	*Speak Up* Ask to be invited/ ask why they weren't invited	*Assert* Assert rights/ capabilities/ highlight that treatment is wrong/ explain their behaviour
Sad Unhappy/ hurt/ sad/ down/ insecure	*Fair* Treatment is fair/ good	*Leave* Not go back/ stop working there	*Maintain Status Quo* There is no issue/ I don't want to talk about it
Angry Angry/ annoyed/ frustrated/ cross	*Questioning* Why wasn't I invited?	*Nothing* Unsure/ nothing/ stay quiet/ leave it	*Inclusion* To be included/ invited
	Assertive They're not worth it	*Seek Support* Get staff to speak to manager	

Appendix L: Initial Overall RIDS Coding Frame

Category	Typology	Description	Examples
Emotions **An emotional reaction experienced in response to treatment depicted in the story**	Content	A positive emotion related to feeling content, pleasant	Good, ok, alright, fine, happy
	Ambivalent	Not emotionally affected, unphased.	Not bothered
	Sad	An emotion related to feeling down, hopeless, or low in mood	Sad, upset, unhappy, low, down, hurt, lonely
	Fearful	An emotion related to anxiety, nervousness, or unease	Scared, panic, worried, insecure, rejected
	Angry	An emotion word related to annoyance, hostility, contempt	Angry, annoyed, frustrated
	Uncoded	Not answered, or an answer which does not describe an *emotion,* or where possible emotion is ambiguous e.g. "I feel left out", "Awful", or "Bad".	
Cognitions **Perception of the quality of the treatment depicted in the story.**	Fair	Perception that treatment received is respectful, good, fair	That's fine, ok, good.
	Indifferent	Perception that treatment is neither good nor bad, has no impact, or unsure if treatment is good or bad, questioning	It's only names, you never know what's happened to him
	Unfair	Perception that treatment received is discriminatory	That's not right, disrespectful, wrong, unkind, unfair
	Deemed incapable	Perception that they have been underestimated or misjudged	They don't know what I can do, they don't understand me
	Endorsing	Perception that negative treatment is true and justified or has been internalised	I'd think it was true
	Uncoded	Not answered, or an answer which does not relate to how the participant regards the quality of the interaction, or their response to it.	

Behaviour **An action (or lack of action) in direct response to the treatment and their perception of the interaction.**	Speak up	Action that communicates unhappiness in the moment to the perpetrator	Tell him to speak to me, tell them, tell them what they are doing is wrong
	Report	Action that communicates unhappiness following the incident to another person	Call police, speak to carer, report to tutor, talk to mum
	Prove wrong	Perform action which shows treatment is unjustified/ untrue	Go out and get a job, show them what I can do
	Leave	An active action to get out of situation, including not returning	Run away, not go back, stop working there
	Nothing	Take no action towards treatment or ignore it/ pretend is not happening	Nothing, just go along with it, leave it, unsure, ignore
	Uncoded	Not answered, or an action which does not relate to the given situation.	
Motivation **The reason why the action was chosen, which may also include the hoped-for outcome.**	Challenge (Includes: Assert, Educate, and Change Behaviour)	To show that treatment is wrong and/or what correct and preferred action should be. Assert rights and capabilities, educate the other, or try and change their behaviour.	It's the right thing to do, to change the way he behaves, make people more aware, to be included.
	Feel better	To seek emotional/ practical support, from self or other, to feel better	Get it off my chest, makes me feel better
	Punish	To punish the other for poor treatment	Arrest him, get into trouble, get them sacked
	No need for action	If treatment is perceived as fair, no response may be required	Nothing, I have no right to be there
	Avoid (Includes: Fear of escalation, repercussions, and confrontation)	To avoid an escalation in treatment or fear of intervening in the situation	I don't like confrontation, I'd be scared of what he'd do next
	Resignation	A belief that nothing would help, while recognising that treatment was unfair	It's just how things are, there's no point
	Uncoded	Not answered, or if response does not relate to *why* the given action was taken.	

Appendix M: RIDS Final Coding Frame

Category	Typology	Description	Examples
Emotions **An emotional reaction experienced in response to treatment depicted in the story.**	Content	A pleasant emotion related to feeling content, joy, happiness.	Good, ok, alright, fine, happy
	Ambivalent	Not emotionally affected, unphased.	Not bothered
	Sad	An emotion related to feeling down, hopeless, or low in mood	Sad, upset, unhappy, low, down, hurt, lonely
	Fearful	An emotion related to anxiety, nervousness, or unease	Scared, panic, worried, insecure, rejected
	Angry	An emotion word related to annoyance, hostility, contempt	Angry, annoyed, frustrated
	Uncoded	Not answered, or an answer which does not describe an *emotion,* or where possible emotion is ambiguous e.g. "I feel left out", "Awful", or "Bad".	
Cognitions **Perception of the quality of the treatment depicted in the story.**	Fair	Perception that treatment received is respectful, good, fair	That's fine, ok, good.
	Indifferent	Perception that treatment is neither good nor bad, has no impact, or unsure if treatment is good or bad, questioning	It's only names, you never know what's happened to him
	Unfair	Perception that treatment received is poor, bad, wrong	That's not right, disrespectful, wrong, unkind, unfair
	Deemed incapable	Perception that skills and capabilities have been wrongly underestimated	They don't know what I can do, they don't understand me
	Endorsing	Perception that negative treatment is true and justified or has been internalised	I'd think it was true
	Uncoded	Not answered, or an answer which does not relate to how the participant regards the quality of the interaction. Includes ambiguous responses, for example, "the doctor doesn't take care of you".	

Behaviour **An action (or lack of action) in direct response to the treatment and their perception of the interaction.**	Speak up	Action that communicates unhappiness in the moment to the perpetrator	Tell him to speak to me, tell them what they are doing is wrong
	Report	Action that communicates unhappiness following the incident to another person	Call police, speak to carer, report to tutor, talk to mum
	Prove wrong	Perform action which shows treatment is unjustified/ untrue	Go out and get a job, show them what I can do
	Leave	An active action to get out of situation, including not returning	Run away, not go back, stop working there
	Nothing	Take no action towards treatment or ignore it/ pretend is not happening	Nothing, just go along with it, leave it, unsure, ignore
	Uncoded	Not answered, or an action which does not relate to the given situation. Includes ambiguous responses, for example, "Ask them how the meal was".	
Motivation **The reason why the action was chosen, which may also include the hoped-for outcome.**	Challenge (Includes: Assert, Educate, and Change Behaviour)	To show that treatment is wrong and/or what correct and preferred action should be. Assert rights and capabilities, educate the other, or try and change their behaviour.	It's the right thing to do, to change the way he behaves, make people more aware, to be included.
	Feel better	To seek emotional/ practical support, from self or other, to feel better	Get it off my chest, makes me feel better
	Punish	To punish the other for poor treatment	Arrest him, get into trouble, get them sacked
	No need for action	If treatment is perceived as fair, no response may be required	I have no right to be there
	Protection (Includes: Fear of escalation, repercussions, and confrontation)	To protect the self from further harm, prevent the situation from escalating, or striving to avoid negative outcomes.	I don't like confrontation, I'd be scared of what he'd do next
	Resignation	A belief that nothing would help, while recognising that treatment was unfair	It's just how things are, there's no point
	Uncoded	Not answered, or if response does not relate to *why* the given action was taken. Includes ambiguous responses, for example, "It would solve the problem".	