Measuring and conceptualising self-stigmatisation and associated factors in people with intellectual disabilities

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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.

Signature:

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Overview

Self-stigmatisation refers to the process by which members of a discriminated group endorse stigmatising stereotypes, thus increasing their sense of being different and accepting their lower quality of life as being justified. There is a significant body of research on how it can affect people with mental health problems, but our understanding of how and whether people with intellectual disabilities (ID) internalise the negative attitudes of others is limited.

Part one is a literature review that considers the current evidence on how levels of self-stigma impact behaviour in individuals with severe and enduring mental health problems. The review suggests that higher levels of self-stigma are associated with behaviours that may be detrimental to recovery, such as poorer treatment adherence and reduced social contact.

Part two presents the findings of a study that aimed to create a psychometrically-sound measure of self-stigma for use with people with ID, and to understand how self-stigma relates to other psychosocial factors, such as psychological distress and self-esteem, as well as sociodemographic characteristics. The self-stigma scale was not found to be psychometrically sound but a relationship was established between psychological distress and negative reaction to stigmatisation and gender, as well as between self-esteem and sense of power.

Part three considers changes that could have been made to the methodology, both in terms of the development of the measure and its administration to increase its reliability.

This was a joint project with Kristina Fenn, who undertook a feasibility study of a programme aimed at increasing stigma resistance in people with ID.

Impact Statement

Attitudes towards individuals with intellectual disabilities (ID) have improved over recent decades but this group continues to be one of the most socially devalued and stigmatised groups. This can be observed in the high levels of bullying and disability hate crime. There have been a number of initiatives to educate the general public about ID with the hope of improving inclusion and reducing negative attitudes. However, there has been less work with people with ID to think about how they view themselves, whether they agree with the negative views held by others, and where self-stigmatisation exists, if it affects how they feel and behave.

Part of the reason for the dearth of research in this area is the lack of a measure to assess self-stigma in people with ID. The intention of this study was to create an appropriate measure of self-stigma for people with ID, as well as to investigate whether self-stigma relates to other psychosocial factors, such as psychological distress, self-esteem and sense of power in a similar way as has been observed in people with mental health problems where there has been significantly more research.

The study highlighted the difficulty of using self-report measures with people with ID. Although there is evidence to suggest that self-report measures can be used reliably with people with ID, the psychometric analysis from this study showed caution needs to be exercised when measures are adapted and administered. It would be a backward step to suggest that researchers should not continue to develop measures specifically for this population, and one solution might be to involve with people with ID earlier on in the development of the measure. However, it is also important to acknowledge that methodologies that rely heavily on language may not be appropriate for people with mild to moderate ID, however, much they have been adapted, and researchers should be looking at other methodologies to assess attitudes in this population.

Although issues with the reliability of the measure meant that findings should be read with caution, the study suggests that if an individual feels angry or embarrassed by others' attitudes or chooses to withdraw socially as a result of negative stereotypes associated with ID, this may have a negative impact on their well-being. Accordingly, interventions that help individuals to respond differently to negative attitudes may have a positive impact on their mental health.

The results also suggested that there is a positive relationship between self-esteem and sense of power. This highlights the importance of having fora where individuals with ID are heard, as well as ensuring that people with ID are empowered to make more decision for themselves. It is not only important in its own right but may also have the benefit of increasing self-esteem.

The literature review, considered the current evidence on how levels of self-stigma impact behaviour in individuals with mental health problems. It indicated that higher levels of self-stigma are associated with behaviours that may be detrimental to well-being, suggesting that reducing self-stigma is a key part of the recovery process.

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Part 1: Literature Review

A systematic review of the impact of self-stigmatisation on the behaviour of individuals with severe and enduring mental health problems

Abstract

Aim

To review the current evidence on how levels of self-stigma relate to behaviours that could negatively affect recovery in individuals with severe and enduring mental health problems (SEMs).

Method

The PsycINFO, Scopus and CINAHL databases were searched for studies which reported on the relationship between self-stigma and behaviours that are key to recovery and wellbeing: treatment adherence, employment, social contact, and help-seeking in individuals with SEMs.

Results

The search identified 22 articles, of which 20 met the quality threshold and were included. Most reported the relationship between self-stigma and treatment adherence (n=13), with less attention given to the relationship between self-stigma and social contact (n=5), or employment (n=2). One study, excluded from full review due to its quality, explored the relationship between self-stigma and mental health service use. The review suggests that higher levels of self-stigma are associated with behaviours that may be detrimental to recovery, such as poorer treatment adherence and reduced social contact.

Conclusion

Higher levels of self-stigma are associated with behaviours that may be detrimental to well-being and recovery. However, there needs to be more research to

understand how self-stigma is related to behaviour and if this is the same for people with different mental health conditions.

Introduction

Over the past 15-20 years there has been a move to research self-stigma as a concept separate from stigma, and a number of systematic literature reviews have been published on this subject. This has included a review of the consequences and correlates of self-stigma (Livingstone & Boyd, 2010) and a review of stigma resistance (Firmin, Luther, Lysaker, Minor & Salyer, 2016). These reviews, however, have been focussed on the psychosocial factors, such as hope, self-esteem and power but have not considered the behavioural changes that can occur as a result of self-stigmatisation. This review hopes to bring together the research that has investigated how self-stigma in people with severe and enduring mental health problems (SEMs) might be associated with behaviours that have a deleterious impact on recovery.

SEMs can have a devastating impact on the lives of those affected. Beyond the distress and disability caused by the SEM, the stigma of being labelled with an SEM can cause significant harm and prevent people from reaching their life goals (Corrigan, Larson & Rüsch, 2009). Nine out of ten people who have mental health problems report feeling stigmatised (Corker et al., 2016), for example, people diagnosed with schizophrenia are often assumed to be dangerous (Ben-Zeev, Young & Corrigan, 2010), or to lack control and behave unpredictably (Harrison & Gill 2009). However, it is not just the stigmatising views of others that can have a negative impact on people with SEMs, but also self-stigma, which can lead to a reduced quality of life.

Self-stigma is the internalisation of ideas and beliefs about the self being less valued (Corrigan & Watson, 2002). It refers to the process by which members of a discriminated group endorse stigmatising stereotypes, thus increasing their sense of being different and accepting their lower quality of life as being justified. This process is different from individuals in discriminated groups just being aware of stigma; rather it describes the process by which an individual incorporates negative stereotypes held by others into their sense of self and identity, increasing the sense of stigmatisation above and beyond the direct effect of stereotyping and discrimination by others.

Corrigan's (2000) social-cognitive model of mental health stigma identifies three components: stereotype, prejudice and discrimination, which can be used to understand self-stigma. Stereotype refers to negative beliefs held about the self, such as "I am incompetent" or "I am weak" (because I have a mental health problem). Knowledge of a stereotype about oneself does not necessarily lead to the individual endorsing the stereotype, but in circumstances where the stereotype is endorsed, the second component, prejudice, is realised. Endorsement of the negative belief will then result in negative emotional reactions, such as low self-esteem and low self-efficacy. Prejudice is a cognitive, affective process, which can lead to a behavioural reaction, referred to in the model as discrimination. In self-stigma, discrimination can lead to, for example, individuals not pursuing work opportunities because of a belief that they will be rejected. Livingstone and Boyd (2010) suggests that self-stigma can lead to negative feelings (about self), maladaptive behaviour and identity transformation because of an individual's experience, perception, or anticipation of negative reactions in social interactions due to his or her mental health status.

Corrigan (2009) hypothesised that self-esteem and self-efficacy act as mediators between internalised stigma and changes in behaviour among members of stigmatised groups. Accordingly, reduced levels of self-esteem and self-efficacy can lead to individuals with high levels of self-stigma believing that there is no point in trying to reach their life goals. This hypothesis is supported by evidence that people who have been labelled with SEMs will anticipate stigmatising behaviour from others (Thornicroft 2003) and believe that they will be rejected and devalued (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). As a consequence, individuals with SEMs may avoid activities, such as social engagements, medical treatment and employment.

The recovery model in mental health (NHS England, 2011) emphasises the importance of hope for people experiencing mental health problems. It also speaks about the importance of people having meaningful lives and supportive networks. Existing models of self-stigma hypothesise that increased levels of self-stigma could undermine recovery as people are prevented from engaging in activities, such as work and spending time with others, that are likely to take them further along the recovery journey. Self-stigma may also impede recovery for people with SEMs as they are less likely to seek help, and to adhere to treatment once started (Corrigan, 2004). It has therefore been suggested that interventions to reduce self-stigma, and associated behaviours that are likely to impede recovery, should be an important part of the treatment plan for people with mental health problems (Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012; Yanos,Lucksted, Drapalski, Roe, Lysaker, 2015).

Research into stigma and self-stigma has increased in recent years, however, much of the work has focused on the impact of stigma and self-stigma on cognitive processes such as attitudes and intentions, rather than behaviour. A systematic review of the relationship between stigma and help-seeking (Clement et al., 2015) observed a negative relationship between all types of stigma and help-seeking. However, almost all the studies reviewed explored the relationship between attitudes and intentions towards seeking help and self-stigma, rather than actual help seeking behaviours. Similarly, a larger body of research has studied the relationship between self-stigma and quality of life, or changes in self-esteem and self-efficacy (Abiri, Oakley, Hitchcock & Hall, 2016) but again this does not identify changes in behaviour.

This review draws together existing research to develop a better understanding of how behaviours are influenced by self-stigma, carrying out a meta-analysis where there is sufficient data. The behaviours considered are employment, social contact (including intimate relationships), help-seeking and treatment adherence, all of which are considered to affect recovery. These behaviours were included as they had been either hypothesised or shown to be associated with self-stigma and stigma (Corrigan, 2004, 2009; Thornicroft, 2003).

In relation to adherence to medication and psychological therapies this review adopts a medical model, with the assumption that adherence is a positive and helpful behaviour. It is, however, acknowledged that this is a simplified approach for the purpose of this review. This definition does not make allowance for a person’s reasoned decision to opt to discontinue care to avoid negative effects or that adherence to medication in itself could be stigmatising (Corrigan, P.W., Druss, B.G., & Perlick, D.A., 2014).

It focuses only on behavioural changes associated with high levels of self-stigma and not cognitive changes, such as attitudes and intentions, although the distinction between behaviours and attitudes or intentions can be hard to make. Researchers often rely on self-report measures rather than direct observations for measuring behaviours, and it could be argued that a person's self-report is as much a reflection of their intended behaviour as it is of their actual behaviour. For the sake of this review a study was included if the researcher's aim was to measure behaviour, rather than cognitions. The review does not include the behaviour of disclosure, such as telling others about one's diagnosis or experience or mental health problems. Disclosure can be seen as a mediator; a person's decision about whether or not to disclose their mental health problems is likely to influence whether they decide to engage in other behaviours such as forming or maintaining relationships, seeking employment, or engaging with treatment.

In the review, SEMs will be defined in line with the National Institute of Mental Health's broad definition (1987), which defines an individual as having an SEM if their mental health problems have a functional impact, and the duration and treatment of it is long-term. To that extent individuals must have a clinical diagnosis and be in receipt of mental health treatment either as an outpatient, day patient or inpatient. The decision to include all SEMs in the review rather than focus on one particular SEM was partly pragmatic as there were a limited number of studies that reported on the relationship between behaviour and self-stigma. By including all SEMs this maximised the number of papers that could be included. In addition, however, by including studies that explored the effects of self-stigma on behaviour in individuals with all SEMs, it was possible to see if self-stigma and behaviour had a different association, where a different diagnosis had been given.

Research question

This review aims to answer the following question: How does self-stigmatisation affect employment, relationships, help-seeking, medication and treatment adherence, and social contact in people with SEMs?

Method

Inclusion Criteria

This review included studies meeting the following criteria: (1) the target population were adults (over the age of 18) with a clinically diagnosed or clinically confirmed SEM, in receipt of mental health treatment as an outpatient, day patient or inpatient; the study (2) used a validated measure of self-stigma; (3) was published in a peer-reviewed journal; and (4) in English. Studies that fulfilled these criteria were then assessed using a quality appraisal tool and those studies which did not meet the quality threshold were excluded.

A meta-analysis was done where there were sufficient papers to making a meaningful comparison. The reporting of a correlational relationship between self-stigma and behaviour was not a criterion for inclusion in the review.

Search Strategy

Three electronic databases (PsycINFO, Scopus and CINAHL) were searched in October 2017 to identify studies which fulfilled the inclusion criteria. The search used these databases as it was felt that they were most likely to cover the psychological construct of self-stigma. Databases that focus on medical and pharmaceutical journals, such as Embase or Medline, were not included because the review was not related to any particular psychiatric diagnosis.

The databases identified relevant studies which included in the title, keywords or abstract the search terms self-stigma (“self stigma" and “internali*ed stigma”) and mental health problems (“mental disorder”, “psychiatric disorder”, “mental ill-health”, “mental illness”, schizophrenia and schizo*) as well as the behaviours detailed in Table 1. There was no time-limit imposed on the search. The references in the final papers, along with relevant systematic reviews were also checked.

Table 1 - Search terms and synonyms for included behaviours

Employment	Social contact	Help-seeking	Treatment adherence
Career Employ* Job Occupation Profession Trade Vocation Work	Acquaintance Friend* Marri* Marriage Partner Relationship Significant other Social avoidance Social participation Spouse	Healthcare seeking Healthcare utilization Treatment barriers	Attendance Appointment Compliance Concordance Drug Medication Medic* Pharma* Treatment Therap*

Study selection

The abstract and title of all papers were read to determine whether they met the criteria that had been set. The results section were also checked to ensure that there was a measure for both self-stigma and the relevant behaviour. Where it was not possible to establish if the paper met the criteria from this information alone, the entire paper was read.

Data extraction

Basic information about the study was recorded. This included the study design and the country in which it was carried out, the characteristics of the sample including age, gender and SEM disorders, the measures that had been used to assess behaviours and self-stigma, and findings relating to the association between self-stigma and behaviour. A second researcher verified the findings for the studies that were included in the meta-analysis.

Meta-analysis

A meta-analysis was conducted for the relationship between medication adherence and self-stigma. This was the only behaviour where there was a sufficient number of studies using the same or a similar measure, to conduct a meaningful comparison. Of the nine studies that reported on the relationship self-stigma and medication adherence, five reported the correlation between the same measure of self-stigma and the same or similar measure of medication adherence.

The directly reported correlation coefficients were used as the effect sizes. Where correlation coefficients had not been reported in the paper, the authors were contacted directly to ask if they could provide the relevant information. Of the four authors who were contacted one responded with the relevant correlation coefficient, resulting in six studies being included in the meta-analysis

Analytic procedures

Weighted mean effects size and heterogeneity test (Q statistics) were calculated using STATA. The correlation coefficients were transformed using Fisher's r-to-Z transformation in order to reduce the skew of the standard error

(Rosenthal, 1991). The formula is defined below, where ES_{zr} is Fisher's Z and r is the reported correlation.

$$\mathrm{ES}_{zr} = .5^{*}\log_{e}\left\lfloor\frac{1+r}{1-r}\right\rfloor$$

The standard error was then calculated. The formula is defined below, where *n* represents the number of participants contributing to the effect size.

$$\mathrm{SE}_{zr} = \sqrt{\frac{1}{\mathrm{n}-3}}$$

Finally the effect sizes were weighted in order that the larger studies, with less error, carried a greater weight. The weighted effect size was calculated using the following formula.

$$\mathrm{W}_{zr} = \frac{1}{(\mathrm{SE}_{zr})^{z}} = \mathrm{n}\text{-}3$$

A random effects model was used for the meta-analysis which allows the results to be generalised to the whole target population and not just those included in the current sample (Field, 2001). It is also recommended by the National Research Centre (1992) who warn against using a fixed effects model when assumptions of homogeneity have been violated. Where there is heterogeneity a random effects model will reduce the likelihood of type I error (Diener, Hilsenroth & Weinberger, 2009). To test for heterogeneity a Q-statistic was calculated for the meta-analysis. A significant Q-statistic indicates that the distribution of effect sizes around the mean is greater than would be expected based on the sampling error.

An I^2 statistic was also calculated to estimate what proportion of the total study variance was as a result of between study variance. Cut-offs of 25%, 50% and 75% represent low, medium and high variance (Higgins, Thompson, Deeks &

Altman, 2003). It was calculated using the following formula where Q represents the Q-statistic and df represents the degrees of freedom.

$$I^2 = 100 * \frac{Q-df}{Q}$$

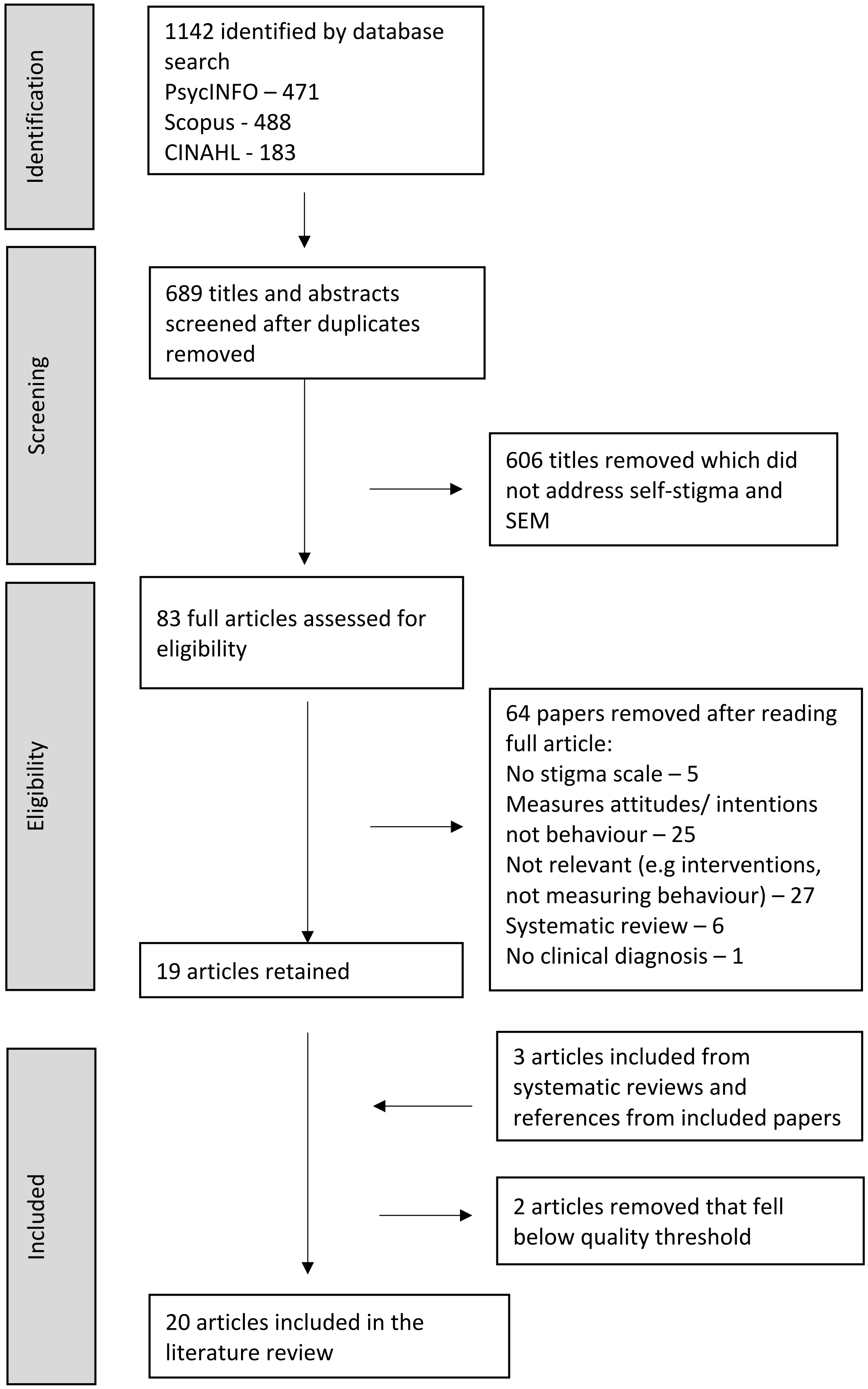
Results

The search yielded 20 articles (fig. 1) which reported on studies with a total of 2516 participants. The majority of the participants (57%) had a diagnosis of schizophrenia or schizoaffective disorder. Other diagnosed mental health disorders included bipolar disorder (16%) and depressive disorder (12%). The diagnosis was made by the participant's healthcare professional and in some studies was also confirmed by a researcher. Seven of the studies had participants with different SEMs. One study (Sarisoy et al., 2013) made a comparison between the behaviour of individuals with a diagnosis of schizophrenia and a diagnosis of bipolar disorder, but the other studies only reported the overall effect size of the participants and did not draw a comparison between the individuals with different diagnoses. Research suggests that schizophrenia and other schizoaffective disorders are more stigmatised than other SEMs (Angermeyer & Matschinger, 2003), and therefore in combining the effect sizes, regardless of diagnosis, it may have exaggerated the relationship between self-stigma and behaviours in less stigmatising disorders.

Of participants, 37% were from North America and Western Europe, 25% from the Far East, 14% from Africa, 12% from the Middle East, and 12% from Eastern Europe. Previous research has shown that attitudes to mental health problems vary between cultures (Angermeyer et al., 2004), and that mental health problems are more stigmatised in cultures that are more collectivist (Hsu et al., 2008). These differences in cultures have also been shown to have an impact on the way people with mental health problems behave and are treated by others (Corrigan et al., 2008).

The studies all used non-experimental designs, and most were cross-sectional (91%). Data were gathered through a combination of standardised questionnaires, researcher developed questionnaires, face-to-face interviews and collection of observational data.

Figure 1 – Flow diagram of search process



Quality Assessment Tool

A quality assessment tool was used in order to ensure the reliability and validity of the studies and to assess whether they had been designed, conducted and carried out in such a way to minimise errors and bias. Through excluding papers which were judged as being of poorer quality it makes it more meaningful to generalise the findings of the studies that were included. There are a limited number of tools that can be used for non-experimental studies, particularly when both cross-sectional and longitudinal studies are being judged using the same tool, however, the QualSyst (Kmet, Lee & Cook, 2004) ,which was used in this review, was designed for this purpose.

The QualSyst tool (Appendix 1), consists of 14 items scored as yes (2), partial (1), or no (0), depending on the extent to which the criterion is met, with each criterion given an equal weight. The instructions for using the tool indicate which items should be used depending on the type of study design that is being assessed. For the cross-sectional studies, nine of the criteria were used giving a possible score of 18, and for the longitudinal studies ten criteria were used with a maximum score of 20. In order to compare the different studies using a different number of criteria, Kmet et al. (2004) recommend that a summary percentage is calculated and suggest that 75% represents a relatively conservative threshold for inclusion and that 55% represents a relatively liberal threshold. To check for consistency of rating, five papers were independently rated by a second reviewer. The scores were the same or within one mark of each other, indicating consistency in scoring.

Table 2 – Quality ratings of articles identified

Study	Question defined	Study design evident and appropriate	Subject selection defined and appropriate	Subject characteristics sufficiently described	Outcome measures defined and robust	Analytic methods described and appropriate	Some estimate of variance reported	Controlled for confounding	Results reported in sufficient detail	Conclusion supported by results	Summary percentage scores (%)
Adewuya et al., 2009	2	1	2	2	1	2	2	-	2	2	89**
Corrigan et al., 2012	2	2	2	2	1	2	0	-	2	2	83**
Cullen et al., 2017	1	1	2	2	2	1	2	-	2	2	83**
Fung et al., 2007	2	1	1	1	2	2	0	-	2	2	72*
Fung et al., 2008	2	2	2	2	2	2	0	-	2	2	89**
Hajda et al., 2015	2	1	2	2	1	2	0	-	1	2	72*
Kamaradova et al., 2016	2	1	2	2	1	2	1	-	0	2	83**
Lee et al., 2011	1	1	2	2	0	2	0	0	0	2	55*
Lien et al., 2016	2	2	2	2	2	2	2	-	2	2	89**
Moriarty et al., 2011	2	2	1	2	1	2	2	-	2	2	89**
Rüsch et al., 2009	2	1	0	2	1	0	0	2	1	1	50
Sarisoy et al., 2013	2	1	1	2	2	2	0	-	2	2	78**
Sedlackova et al., 2015	2	2	2	1	1	2	0	-	2	2	78**
Seglovich et al., 2013	2	2	1	1	2	2	2	-	1	1	78**
Tsang et al., 2009	2	1	1	1	2	2	0	-	2	2	73*
Tsang et al., 2010	2	1	1	0	2	2	0	-	1	2	61*
Villotti et al., 2017	2	1	0	2	2	2	0	2	2	2	75**
Vrbova et al., 2014	2	2	1	2	1	2	1	-	1	2	78**
Yanos et al., 2012	1	2	0	0	2	2	1	-	2	2	67*
Yanos et al., 2008	1	1	0	1	1	1	0	0	2	2	45
Yen et al., 2009	2	2	0	2	2	1	2	1	2	2	80**
Yilmaz et al., 2015	2	1	1	2	2	2	0	-	1	0	72*

** - high quality
* - medium quality

Based on this, two studies which scored below the 55% threshold were removed from the review (Rüsch et al., 2009; Yanos, Lysaker, & Roe, 2008). The Rüsch et al., study scored poorly as there was insufficient information about how the subjects were selected and the analysis that was used. The Yanos et al. study also scored poorly because of a lack of detail about participants, but also poor controlling for confounding factors.

Self-stigma measures

Three validated measures of self-stigma were used in the studies included in this review. The Internalised Stigma in Mental Illness Scale (ISMI; Ritsher, Otilingam & Grajales, 2003), the Self-Stigma of Mental Illness Scale (SSMIS; Corrigan, Watson & Barr, 2006), and the Self-Stigma Assessment Scale (Corrigan & Lundin, 2001). The ISMI consists of five subscales: Alienation measures a sense of being devalued by society; Social Withdrawal measures the extent to which the person is avoiding social contact; Stereotype Endorsement measures the extent to which people agree with prejudices held by others; Perceived Discrimination measures mistreatment which is attributed to the bias of others; and Stigma Resistance measures the extent to which a person can deflect stigma. There was variation in the scales used and the scoring system adopted in different studies. It was translated into Czech, Hebrew, Turkish, Chinese and Yoruba for use in the reviewed studies. Validity and reliability were good in all translated versions, besides the Yoruba translation, for which no psychometric information was provided.

The SSMIS consists of four subscales: Awareness, Agreement, Application and Harm. To complete the measure, the respondent is given a stereotype about a person with mental health problems and asked to rate on a 9-point scale (strongly agree to strongly disagree), to what extent they believe that the public think the stereotype is true (awareness), they personally believe the stereotype to be true (agreement), apply the stereotype to themselves (application), and respect themselves less due to the stereotype (harm). The scale was used in English and Chinese in the included studies. The Chinese version of the SSMIS has good psychometric properties (Tsang et al., 2009).

The Self-Stigma Assessment assesses an individual's attitude to their mental illness, including whether they view themselves as weak, unable to care for themselves, and dangerous. This scale was translated into Taiwanese for the purpose of Yen et al.'s (2009) study. The test had good reliability when translated into Taiwanese but no psychometric information was provided about validity of the translated version.

Outcomes

The behaviours in focus were treatment adherence, employment, social contact and relationships, and help-seeking. The search showed that much of the research (61%) has focussed on adherence to medical and psychosocial treatments, and how this is related to levels of self-stigma. The other studies reported the association between self-stigma and work (10%) or social contact (29%). Only one study (Rüsch et al., 2009) looked specifically at help-seeking behaviour, such as whether people decide to ask for formal or informal help, but was excluded after quality rating due to its low-quality rating. The concept of help-seeking behaviour is, however, also integral to treatment adherence. In the following, the reviewed studies are summarised by behaviour under consideration. In each of the behaviours there are studies included that have not reported effect sizes for the different SEMs and therefore it was not feasible to look at how self-stigma affects behaviours in individuals with different SEMs.

Treatment Adherence

Medication adherence - Nine studies in the review with a total of 1294 participants investigated the relationship between medication adherence and self-stigma (Table 3). Three of these studies investigated the relationship between self-stigma and treatment adherence for individuals with a diagnosis of schizophrenia (Lien et al., 2016; Tsang, Fung & Chung, 2009; Yilmaz & OKanli, 2015), one with individuals with a diagnosis of bipolar disorder (Hadja et al., 2015), and two with individuals with a diagnosis of recurrent depressive disorders (Sedlackova et al., 2015; Yen et al., 2009). The remaining three studies (Adewuya et al., 2009; Kamaradova et al., 2016; Vrbova et al., 2014) studied samples with a combination of different SEMs. Eight of the studies were cross-sectional and one was a prospective study (Yen et al., 2009).

Measuring medication compliance is problematic as it can be costly and inaccurate, and for the most part is done through self-report which can over-estimate compliance but may also be affected by self-stigma. High self-stigma can lead to low self-esteem and low self-efficacy (Corrigan et al., 2009), and therefore may result in individuals having less confidence in their ability to comply and manage their medication, in turn leading to under-estimation of medication adherence.

The Drug Attitude Inventory-10 (DAI-10) (Hogan, Awad & Eastwood, 1983) is a self-report scale commonly used with users of psychiatric services and was used in six of the studies in this review. The measure has been shown to be predictive of medication compliance, however, questions have been raised about its validity (Thompson, Kulkarni & Sergejew, 2000). Ratings are based solely on the judgement of the therapist (Fenton, Blyler & Heinssen, 1997), and it measures a person's attitudes towards medication rather than their compliance with it which could undermine its construct validity. Therefore, while the DAI-10 is the most commonly used measure for assessing medication adherence among users of psychiatric services, there needs to be some caution about its accuracy.

Other measures used by studies in this review are the Medication Adherence Questionnaire (MAQ; Morisky, Green & Levine, 1986), a four-item questionnaire Medication Adherence Rating Scale (MARS; Thompson et al. 2000), the Medication Adherence Scale (Yen et al. 2005) and the Kemp Compliance Scale (Kemp et al., 1996, 1998;). The latter was the only scale used in the reviewed studies which is observer-rated rather than self-rated.

Of the studies included in this review, seven (N=1103) found a negative association between self-stigma and medication adherence, suggesting that people with high levels of self-stigma are less likely to adhere to medical treatment. Both of the studies which reported the relationships between different ISMI subscales (Hadja et al., 2015, Sedlackova et al., 2015) observed a negative relationship between alienation and medication adherence, which would suggest that individuals who feel devalued by society are less likely to adhere to medication. Other relationships between the subscales and adherence differed in the two studies.

Table 3 – Summary of evidence of relationship between self-stigma and medication adherence

Study/Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Adewuya et al. 2009, Nigeria	Cross-sectional observational design. Interview and survey of 342 participants (201 males, 141 females, age (M) - 31.7	Outpatient psychiatric patients with diagnosis (DSM-IV) of schizophrenia (30.7%), depression/anxiety disorders (41.8%), bipolar affective disorder (24%), organic mental disorders (3.5%)	*Self-stigma* – Modified ISMI – Yoruba translation *Medication adherence* – Drugs Attitude Inventory-10 (DAI-10) (Hogan et al., 1983) Medication Adherence Questionnaire (MAQ) (Morisky et al., 1986)	1) Self-stigma higher in those with poor adherence (t = 5.45, p < 0.001) 2) High levels of self-stigma predict poor medication adherence (β = 0.72, p < 0.001)
Hadja et al., 2015, Czech Republic	Cross-sectional observational design. Interview and survey of 33 participants (21 males, 12 females, age (M) - 38.6)	Outpatients with diagnosis (ICD-10) of bipolar disorder	*Stigma* - ISMI – Czech translation *Medication adherence* – DAI-10	1) Negative correlation between total self-stigma (r = -0.49, p<0.05), alienation (r = -0.57, p<0.05), stereotype endorsement (r = -0.42, p<0.05) and medication adherence 2) High levels of self-stigma predict poor medication adherence (F = 7.223, p < 0.05) 3) No difference in self-stigma between those who had and had not discontinued medication in past

Table 3 continued

Study/ Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Kamaradova et al., 2016, Czech Republic	Cross-sectional observational design. Interview and survey with 332 participants (161 males, 171 females, age(M) - 42.7)	Outpatients with diagnosis (ICD-10) of anxiety or neurotic disorder (36%) schizophrenia (18.6%), substance abuse (17.4%), depressive disorder (17.2%), personality disorder (6%) and bipolar disorder (3%)	*Stigma* - ISMI – Czech translation *Medication adherence* – DAI-10	1) Negative correlation between self-stigma and medication adherence (r=-0.49, $p < 0.001$) 2) Higher self-stigma predicted voluntary discontinuation of medication ($F = 29.43$, $p < 0.001$) 3) Higher ISMI scores in those patients who had discontinued medication in the past than those who had not (no statistics provided)
Lien et al., 2016, Taiwan	Cross-sectional observational design. Interview and survey of 170 participants (93 males, 77 females, age(M) - 44.4)	Outpatients with diagnosis (DSM-IV-TR) of schizophrenia or schizoaffective disorder	*Stigma* – ISMI – Chinese translation *Medication adherence* - Medication Adherence Rating Scale (Thompson et al., 2000)	1) Self-stigma higher in non-adherent patients ($t = -2.95$, $p < 0.001$) 2) Negative correlation between self-stigma and medication adherence ($r = -0.25$, $p < 0.01$) 3) Higher ISMI scores predicted lower compliance ($\beta = -0.25$, $p < 0.05$)
Sedlackova et al., 2015, Czech Republic	Cross-sectional observational design. Interview and survey of 68 participants (33 males and 35 females, age (M) - 39.0)	Outpatients with diagnosis (ICD-10) of recurrent depressive disorder	*Stigma* - ISMI – Czech translation *Medication adherence* – DA!-10	1) Negative correlation between total self-stigma ($r = -0.36$, p < 0.005), alienation ($r = -0.36$, $p < 0.005$), stereotype endorsement, ($r = -0.2$, $p < 0.05$), social withdrawal ($r = -0.29$, $p < 0.05$) and stigma resistance ($r = -0.32$, $p < 0.01$) and medication adherence 2) Self-stigma predicted medication adherence ($F = 8.371$, $p < 0.01$) 3) No difference in self-stigma between those who had and had not discontinued medication in past

Table 3 continued

Study/ Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Tsang et al., 2009, Hong Kong	Cross-sectional observational design. Interview and survey of 86 participants (45 males, 41 females, age (M) - 39.9)	Outpatients with diagnosis (DSM-IV) of schizophrenia (DSM-IV)	*Stigma* - SSMIS - Chinese translation *Medication adherence* – DAI-10 Kemp Compliance Scale (Kemp et al., 1996, 1998)	Negative correlation between agreement with negative stereotypes and medication adherence ($r = -0.22$, $p < 0.05$)
Vrbova et al., 2014, Czech Republic	Cross-sectional interview and survey of 74 participants (43 males, 31 females, age (M) - 36.9)	Patients (setting not specified) with diagnosis (ICD-10) of schizophrenia (60%), schizoaffective disorder (19%), schizotypal disorder (10%), acute and transient psychotic disorder (9%), permanent delusional disorder (2%)	*Stigma* - ISMI – Czech translation *Medication adherence* – DAI-10 Data about current medication and discontinuation in the past	Negative correlation between total self-stigma and medication adherence ($r = -0.37$, $p < 0.005$)

Table 3 continued

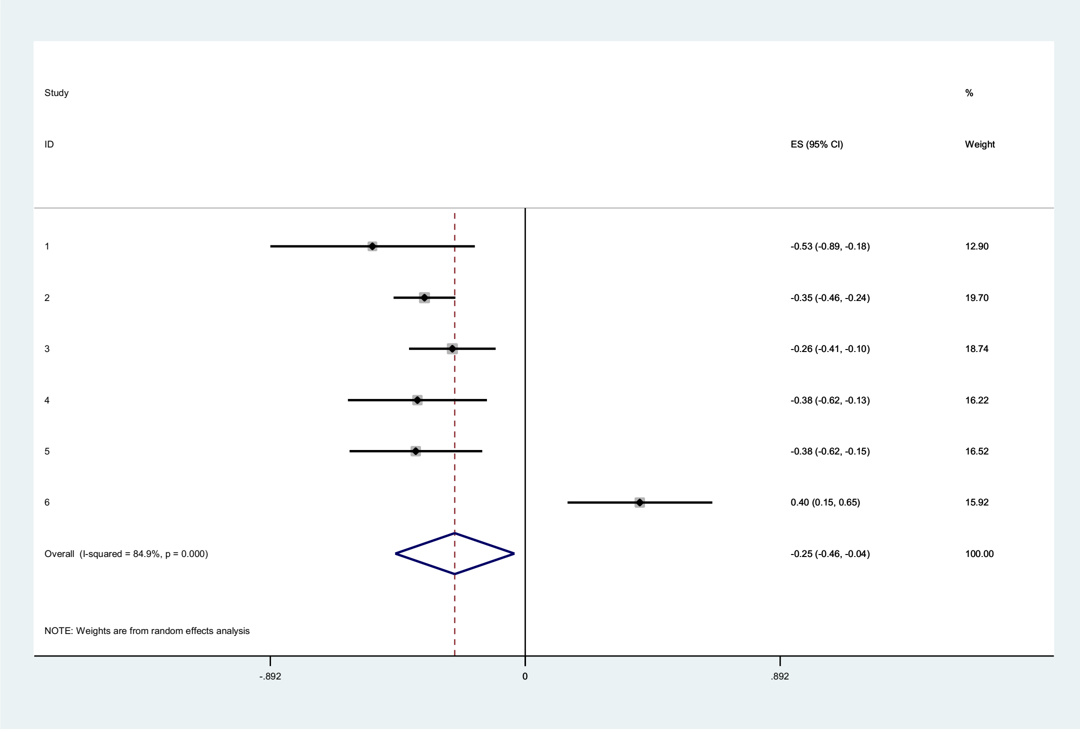
Study/ Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Yen et al. 2009, Taiwan	Cross-sectional and prospective observational design. Interview and survey of 131 participants (50 males, 81 females, age(M) - 42.7) over 12 months	Outpatients with diagnosis of recurrent depressive disorders (DSM-IV)	*Stigma* - Self-Stigma Assessment Scale *Medication* - Medication Adherence Behaviour Scale (MABS) (Yen et al., 2005)	No correlation between self-stigma and medication adherence
Yilmaz et al., 2015, Turkey	Cross-sectional observational design. Interview and survey with 63 participants (47 males, 16 females, age (M) - 38.1)	Outpatient with diagnosis (DSM-IV) of schizophrenia	*Self-stigma* – ISMI - Turkish translation *Medication adherence* – MAQ, DAI-10	Positive correlation between MAQ and self-stigma ($r = 0.26$, $p < 0.01$) and DAI-10 & self-stigma ($r = 0.38$, $p < 0.01$)

A study by Yen et al. (2015) (N=131) found no relationship between self-stigma and medication adherence. It was the only study which had a prospective design and was rated as a high-quality paper. This study, however, differed from the other studies in several ways. Firstly, it was the only study that used the SSAS (Corrigan et al., 2001) to measure self-stigma and the only study which used the MABS (Yen et al. 2005) to measure medication adherence. Secondly, it had a higher proportion of female participants than any of the other studies; 62% of participants were female whereas in all other studies it was below 50%. It is also of note that the study was looking at self-stigma in people with a diagnosis of recurrent depressive disorders. Evidence suggests that in comparison to schizophrenia, depression is a less stigmatised mental health problem (Angermeyer & Matschinger, 2003), and therefore may have less impact on medication adherence. A negative association was found in a similar population in another study (Sedlackova, 2015) but had a relatively small sample size of 66. Finally, one study (Yilmaz et al., 2015) found a positive relationship between self-stigma and medication adherence. This study also had a relatively small sample size of 63 participants and was rated as only of medium quality.

In addition to looking at the relationship between current medication adherence and levels of self-stigma, three studies reported on the relationship between levels of self-stigma and past medication adherence. Two of these (Hadja et al., 2015; Sedlackova et al., 2015) found no differences in levels of self-stigma between those that had discontinued medication and those who had not. In the other study (Kamradova et al., 2016) participants who had voluntarily discontinued medication in the past were more likely to have higher levels of self-stigma. This study had a much larger sample size than the other two and was rated as a high-quality paper.

The meta-analysis of the six studies where a correlation coefficient was available (Hadja et al., 2015; Kamaradova et al., 2016; Lien et al., 2017; Sedlackova et al., 2015; Vrbova, 2014; Yilmaz, 2015) indicated that poor treatment adherence is significantly associated with higher levels of self-stigma (*r* = .28; 95% CI = -0.46, -0.04; *z* = 2.32, *p* = 0.02), representing a small effect size (Cohen, 1990, 1992). The estimated correlation coefficients relative to the overall result is shown in figure 2. The Q-statistic was significant indicating that there was heterogeneity between the studies (Q = 33.02, $p<0.001$) and the I^2 statistic indicated that 84.9% of the variance could be explained through variability in the studies. This represents high heterogeneity (Higgins et al., 2003).

Figure 2 – Forest plot from meta-analysis of correlations between treatment adherence and self-stigma



The evidence from studies in this review suggests that there is an association between high levels of self-stigma and poor medication adherence. However, other than one study carried out in the Czech Republic, the other studies which demonstrated this relationship were undertaken in Asia (Taiwan and Hong Kong), and Nigeria, which are typically seen as more collectivist societies and therefore the results may not necessarily transfer to Western countries with more individualistic cultures. In collectivist societies mental health problems are associated with higher levels of stigma and shame than might be seen in individualist societies and individuals with mental health problems are more likely to be rejected (Adewuya, & Makanjuola, 2005; Griffiths et al., 2006). This in turn may affect behaviours such as medication adherence.

Psychosocial treatment – three studies in the review (N=247), reported across four articles, reported on the relationship between self-stigma and adherence to psychosocial treatments (Table 4). One of these collected data on individuals with a variety of SEMs and reported on the relationship between psychosocial treatment adherence and self-stigma in individuals with all SEMs (Fung et al. 2007), and in individuals with a diagnosis of only schizophrenia (Fung et al., 2008). A further study reported on the relationship in individuals with a diagnosis of schizophrenia (Tsang et al., 2010), and the fourth study on individuals with a diagnosis of bipolar disorder (Lee et al., 2011). Three of the studies were cross-sectional and one was longitudinal (Lee et al., 2011).

Two of the studies (Fung et al., 2007, 2008; Tsang et al., 2010) used the same scales for measuring self-stigma and psychosocial treatment adherence, the SSMIS translated into Chinese and the Psychosocial Treatment Compliance Scale

(PTCS, Tsang, Fung & Corrigan, 2006). The PTCS is scored using a mental health nurse’s observations over a three-month period. The measure has two sub-scales, Attendance and Participation. Attendance measures the actual presence at treatment and Participation measures engagement in and co-operation with treatment. The treatments included were social skills training, vocational training, cognitive behaviour therapy and family intervention. The final study only reported whether participants continued to access psychosocial treatment after a three-month period.

All the studies reported an association between high levels of self-stigma and non-adherence to psychosocial treatment.   In those studies that measured participation and attendance in psychosocial treatments, the relationship with self-stigma varied. The two papers that reported on the same study found a negative correlation between self-stigma and both attendance and participation (Fung et al., 2007, 2008), in both individuals with a diagnosis of schizophrenia as well as individuals with a wider range of SEMs. The other study (Tsang, et al., 2010) demonstrated a relationship between high self-stigma and poor participation in psychosocial treatments but not with attendance in psychosocial treatments.

In the two studies (Fung et al., 2008, Tsang et al., 2010) that reported a regression analysis the outcomes differed. Both sampled individuals with schizophrenia; in one higher self-stigma predicted poorer attendance in psychosocial treatment (Fung et al., 2008), while in the other it predicted poorer participation in psychosocial treatment.

Table 4 - Summary of evidence of relationship between self-stigma and psychosocial treatment adherence

Study/ Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Fung et al., 2007, Hong Kong	Cross-sectional observational design. Interview and survey of 108 participants (51 males, 57 females, av. age 38.5)	Inpatients, day patients and outpatients with diagnosis (DSM-IV) of schizophrenia (79.6%), depressive disorder (6.5%), bipolar affective disorder (8.3%), schizoaffective disorder (3.7%) and delusional disorder (1.9%)	*Stigma* - SSMIS – Chinese translation *Psychosocial treatment adherence* – Psychosocial Treatment Compliance Scale (Tsang et al., 2006)	1) Negative correlation between awareness (r = -0.26, p < 0.01), agreement (r = -0.34, p < 0.01), application (r = -0.43, p < 0.001), harm (r = -0.39, p < 0.001) and attendance at prescribed psychosocial treatment. 2) Negative correlation between agreement (r = -0.32, p < 0.001), application (r = -0.39, p < 0.001), harm (r = -0.39, p < 0.001), and participation in prescribed psychosocial treatment
Fung et al., 2008, Hong Kong	Cross-sectional observational design. Interview and survey of 86 participants (44 males, 42 females, age(M) - 39.9)	Inpatients, day patients and outpatients with diagnosis (DSM-IV) of schizophrenia	*Stigma* - SSMIS – Chinese translation *Psychosocial treatment adherence* – Psychosocial Treatment Compliance Scale	1) Negative correlation between awareness of negative stereotypes (r = -0.27, p < 0.05), agreement (r = -0.37, p < 0.01), application (r = -0.44, p<0.01), harm (r = -0.42, p < 0.01) and attendance at prescribed psychosocial treatment. 2) Negative correlation between agreement (r = -0.33, p < 0.01), application (r = -0.40, p < 0.01), harm (r = -0.39, p<0.01), and participation in prescribed psychosocial treatment. 2) Higher levels of self-stigma (agreement) predicted poor attendance in psychosocial treatment (β = -0.424, p < 0.001)

Table 4 continued

Study/ Country	Design & sample (gender, age)	Sample characteristics	Measures of self-stigma and behaviour	Findings
Lee et al. 2011, US	Longitudinal observational design. Data collection of 29 participants (14 males, 15 females, age(M) - 44)	Outpatients with diagnosis of bipolar disorder (source of diagnosis not given)	*Stigma* – ISMI *Psychosocial treatment adherence* - Clients still in treatment after 3 months	1) Non-adherence associated with higher levels of self-stigma ($p < 0.05$)
Tsang et al., 2010, Hong Kong	Cross-sectional design. Interview and survey of 105 participants (51 males, 54 females, age(M), 41.8)	Outpatients and day patients diagnosed with schizophrenia (DSM-IV)	*Stigma*- SSMIS – Chinese translation *Psychosocial treatment adherence*- Psychosocial Treatment Compliance Scale	1) Negative correlation between, application ($r = -0.32$, $p < 0.01$), harm ($r = -0.28$, $p < 0.01$) and participation in prescribed psychosocial treatment. 2) No correlation between self-stigma and attendance in prescribed psychosocial treatment 2) Higher self-stigma (harm) predicted poorer participation in psychosocial treatment ($\beta = -0.225$, $p < 0.01$)

Two of the studies used the SSMIS to measure self-stigma, and the results showed different subscales of self-stigma had a relationship with psychosocial treatment adherence. In one study (Fung et al., 2007, 2008), there was a negative correlation between awareness, agreement, application and harm and attendance in psychosocial treatment, and a negative correlation between agreement, application and harm in participation in psychosocial treatment. The results were the same when looking at the relationship in individuals with a diagnosis of schizophrenia (Fung et al., 2008) and individuals with different SEMs (Fung et al., 2007). However, in the other study (Tsang et al., 2010) there was only a relationship between the agreement and harm subscales of the SSMIS and participation in psychosocial treatment.

In the two studies that reported a regression, again there was a difference in which self-stigma subscales were predictive of psychosocial treatment adherence. Tsang et al., (2008) reported that only the harm subscale predicted participation in psychosocial treatment, which suggests that when an individual's self-esteem is affected by self-stigma they are less likely to engage in or co-operate with psychosocial treatment. Fung et al., (2008), however, reported that only high levels of self-stigma agreement predicted poor attendance in psychosocial treatment. Taken together, these results suggest that individuals with high levels of self-stigma are less likely to engage in psychosocial treatments. However, as with the studies that reported on the relationship between self-stigma and medication adherence, the reviewed studies were mostly carried out in collectivist societies, and therefore some caution needs to be taken in generalising the results to more individualistic cultures.

Employment

Two studies (N=264) in this review explored the relationship between work and self-stigma (Table 5). One reported on the relationship between employment history and self-stigma, the other at the relationship between self-stigma and work productivity. Although reporting on different aspects of employment, both studies found that individuals with high levels of stigma were less likely to achieve meaningful employment goals which could in turn improve the chance of recovery.

Corrigan and Powell (2012) reported on the relationship between self-stigma and employment history in individuals with a variety of SEMs using a cross-sectional design. Self-stigma was measured used the SSMIS and employment history using a modified version of the self-report Social Adjustment Scale (Weissman et al., 2001). It was adjusted to include information about whether individuals had worked in the last three months, last year or ever. Employment could include paid and unpaid work, both full- and part-time. They found no relationship between stigma awareness or agreement and an individual's employment history. However, stigma application was negatively correlated with whether an individual had worked either in the last three months or in the last year, and stigma harm was negatively correlated with all elements of employment history. These results are reflective of the proposition made by Corrigan et al., (2012) that just being aware of negative stereotypes and agreeing with them is not sufficient to affect behaviour but rather when an individual applies negative stereotypes to themselves or it impacts on their self-esteem that behaviour changes are likely to be seen.

Table 5 – Summary of evidence of relationship between self-stigma and employment

Study/ Country	Design & sample (gender, age)	Sample Characteristics	Measures of self-stigma and behaviour	Findings
Corrigan et al., 2012, US	Cross-sectional observational design. Interview and survey of 85 participants (58 males, 27 females, age(M) - 44.8)	Mental health service users with diagnosis (DSM-IV) of schizophrenia (27%), schizoaffective disorder (26%), bipolar disorder (35%), and recurrent major depressive disorder (12%)	*Self-stigma* - SSMIS *Work* - Modified Social Adjustment Scale (Weismann, Olfson, Gameroff, Feder & Fuentes, 2001)	1) Negative correlation between self-stigma (application) and working in past 3 months (r = -0.19, $p < 0.05$) and last year (r = -0.25, $p < 0.05$) 2) Negative correlation between self-stigma (harm) and working in past 3 months (r = -0.225, $p < 0.05$), last year (r = -0.310, $p < 0.01$) and working ever (r = -0.210, $p < 0.05$)
Vilotti et al., 2017, Canada	Longitudinal observational design. Interview and survey of 170 participants (94 males, 76 females, age (M) - 45.6)	Employees of social enterprise supported work schemes with diagnosis of schizophrenia (49%) or another SEM (51%)	*Stigma* - ISMI *Work* - Endicott Work Productivity Scale (Endicott & Nee, 1997)	1) Self-stigma negatively related to work productivity (r = -0.37, $p < 0.001$).

Vilotti et al. (2017) carried out a longitudinal study of supported employment schemes, and explored the mediating effect of self-stigma between workplace social support and perceived work productivity. Self-stigma was measured using the ISMI, and work productivity was measured using the Endicott Work Productivity Scale (Endicott & Nee, 1997) which considers attendance (absenteeism and time on task), quality of work, performance capacity and personal factors (social, mental, physical and emotional). The study showed that self-stigma was negatively related to workplace productivity and had a significant mediating effect between work place support and perceived productivity. This suggests that even when there is support in the work place for people with SEM, the effectiveness of this support may be diminished if the individual experiences high levels of self-stigma.

Social contact

The review included five studies (N=711) that reported the relationship between self-stigma and social contact and relationships (Table 6). Three of the studies were interested in the relationship in individuals with a diagnosis of schizophrenia, one compared individuals with a diagnosis of bipolar and schizophrenia, and thle final one sampled participants with different SEMs. Each study reported on different aspects of social contact and relationships, considering both the number of times that individuals had contact with friends and family, and their ability to engage in relationships.

Table 6 – Summary of evidence of relationship between self-stigma and social contact and relationships

Study/ Country	Design & sample (gender, age)	Sample Characteristics	Measures of self-stigma and behaviour	Findings
Cullen et al., 2017, US	Cross-sectional observational design. Interview and survey of 271 participants (127 males, 144 females, age (M) - 42)	Users of urban outpatient psychiatric clinic with clinically diagnosed bipolar spectrum disorder (45%), schizophrenia spectrum disorder (33%), major depression with psychotic features (15%), and psychotic disorder NOS (7%)	*Stigma* – ISMI (Modified 12-item scale) Resistance) *Social contact* – No. of friends & relatives in contact with and frequency of contact	1) Level of self-stigma associated number of friends in contact with (*F*= 4.81, p<.001) and relatives in contact with when adjusted for demographics and diagnosis (*F*=2.61, *p*=.036)
Moriarty et al., 2011, UK	Cross-sectional observational design. Interview and survey of 50 participants (33 male, 17 females, age (M) - 45.5)	Outpatients with a clinical diagnosis of schizophrenia	*Stigma* –ISMI *Social contact* – Week-long diary of activity	1) Negative correlation between self-stigma total score (r = -0.33, *p*<0.05) and perceived discrimination (r = -0.43, *p*<0.001) and daily activities 2) Perceived discrimination was a significant predictor of daily activities (β=-2.08, *p*<0.001

Table 6 continued

Study/ Country	Design & sample (gender, age)	Sample Characteristics	Measures of self-stigma and behaviour	Findings
Sarisoy et al., 2013, Turkey	Cross-sectional observational design. Interview and survey of 228 participants (107 male, 121 females, age (M) - 35.5)	Outpatients with diagnosis (DSM-IV) with bipolar disorder (52%), and schizophrenia (48%) (	*Stigma* - ISMI – Turkish translation *Relationships* - Multiple Relationships Questionnaire	*Bipolar disorder* - Relational anxiety (z = -2.59, p=0.01) & relational monitoring (z = 3.69, *p*<0.001) higher in individuals with high self-stigma *Schizophrenia* - Relational assertiveness (z = 2.19, p=0.03) lower in individuals with high self-stigma. Relational anxiety (z+-5.74, *p*<0.001) & relational monitoring (z = -2.720, *p*=0.008) higher in individuals with high self-stigma
Segalovich et al., 2013, Israel	Cross-sectional observational design. Interview and survey of 60 participants (48 males, 12 females, age (M) - 39)	Inpatients (30) and outpatients (30) diagnosed with schizophrenia (DSM-IV)	*Stigma* - ISMI – Hebrew translation, *Relationships* - Intimacy Attitude Scale - Revised	*Outpatients* - Negative correlation between self-stigma and the capacity to create intimacy (*r* = -0.59), *p*=0.001) *Inpatients* - no significant correlation
Yanos et al., 2008, US	Cross-sectional observational design. Interview and survey of 102 participants (87 males, 15 females, age (M) - 46.2)	Outpatients diagnosed with schizophrenia (66.7%) and schizoaffective disorder (33.3%) (DSM-IV)	*Stigma* - ISMI *Social contact* - PANSS – social avoidance	Positive correlation between self-stigma and social avoidance (*r* = 0.28, *p*<0.05)

Three studies (Cullen et al., 2017; Moriarty et al., 2011; Yanos et al., 2008) reported on social contact using different outcomes: the number of contacts with family and friends (Cullen et al., 2017), daily activity levels, most of which included social contact (Moriarty et al., 2011), and finally (Yanos et al., 2008) social avoidance using the respective subscale of the Positive and Negative Syndrome Scale (Kay, Oper & Fiszbeln, 1987). The results suggest that self-stigma and social contact are related. Moriarty et al. (2011) was the only study that reported on the subscales; they observed a negative relationships between the perceived discrimination subscale and social contact, suggesting that it is the perceived bias of others that has the largest impact. The findings by Cullen et al. (2017) are in partial agreement. They observed that while individuals with SEMs who have higher levels of self-stigma are in contact with fewer people, the number of times that they see the people they are in contact with is not related to self-stigma.

The remaining two studies (Segalovich et al., 2013; Sarisoy et al., 2013) reported how levels of self-stigma were related to individuals' ability to form intimate relationships. They used different measures to assess intimate relationships but both showed that individuals with high levels of high self-stigma are likely to find it more difficult to form intimate relationships than those with lower self-stigma.

Segalovich et al. (2013) used the Intimacy Attitude Scale (Amidon, Kumar, & Treadwell, 1983), which measures capacity for intimacy. The results showed that there was a significant negative correlation between capacity for intimacy and self-stigma for outpatients but this relationship was not significant in an inpatient population. This could suggest that people with an SEM feel less stigmatised when they are in a setting with others with SEMs and therefore find it easier to have intimate relationships.

The second study that reported on the association between self-stigma and intimate relationships (Sarisoy et al., 2013) used the Multiple Relationships Questionnaire which has nine subscales: relational satisfaction, anxiety, monitoring, esteem, relational control & assertiveness, focusing on relationship extremely, internal & external relationship control. Some of these subscales are less about behaviour and more about attitudes and intentions, but assertiveness within a relationship, pre-occupation with relationships and excessive monitoring of relationships were considered in this review to represent behaviours. The results of this study showed that the relationship between self-stigma and behaviour within relationships varied between individuals with a diagnosis of bipolar disorder and those with a diagnosis of schizophrenia. High levels of relational monitoring were more likely in individuals with both diagnoses who had high levels of self-stigma, as was lower relational assertiveness in individuals with a diagnosis of schizophrenia and high levels of self-stigma. There was no relationship between pre-occupation with relationships and self-stigma in either group.

Discussion

This review sought to examine the relationship between self-stigma and observed behaviours. The findings suggest that there is an association between people with SEMs, who have internalised negative stereotypes about themselves, and behaviours that might otherwise enhance their recovery. This supports the theory that people with SEMs are more likely to adopt the position of “Why Try” as proposed by Corrigan et al. (2009).

The social cognitive model of self-stigma (Corrigan et al., 2006) hypothesises three levels: agreement with negative stereotypes, prejudice and discrimination. The first two levels are cognitive processes by which an individual becomes aware of a negative stereotype and agrees with it. The third level, discrimination, is a behavioural process and occurs when a person applies the stereotype to themselves and changes their behaviour accordingly. According to this model, we would expect behaviour to have a relationship with the application and harm subscales in studies that have used the SSMIS to measure self-stigma. Some of the reviewed studies support this hypothesis but there is also evidence that self-stigma is related at all levels to how individuals behave. In two studies (Fung et al., 2008; Tsang et al., 2009) behaviour was only related to agreement with stigmatising stereotypes.

The evidence from this review supports the notion that high levels of self-stigma are associated with behaviours that are detrimental to mental health and therefore interventions that reduce self-stigma in people with SEMs may lead to positive behaviour changes which could improve individuals' hopes of recovery, and reduce their sense of helplessness. It also seems that a reduction in self-stigma could be associated with the effectiveness of psychosocial interventions; participants are not just more likely to attend treatments if they experience lower levels of self-stigma but they also appear more likely to participate more fully in treatment that is being provided. Secondly, the work by Vilotti et al. (2017) investigating the impact of workplace support for people with SEMs shows that potential positives effects of support on productivity can be negated if an individual has high levels of self-stigma.

Strengths and limitations

A strength of this review was to attempt to move beyond considering how self-stigma affects people's thinking and to pull together the evidence to understand whether high levels of self-stigma are associated with behaviour change, as has been theorised. However, is it important to recognise that the decision to focus on behaviours could also be seen as a limitation as it is difficult to accurately measure behaviour. The majority of the studies included in this review used self-report measures as direct observational methods are time-consuming, expensive and can potentially bias behaviour, but this can lead to inaccuracies. Individuals may over-estimate positive or adaptive behaviours, or in the case of individuals with high levels of self-stigma, their lower self-esteem could conversely result in under-reporting of behaviours such as social contact or medication compliance, thus over-estimating the relationship. In addition, this potential bias could mean that the behaviours being reported are more indicative of intended behaviour than actual behaviour, and this therefore raises the question of whether the research in reality is exploring anything beyond how self-stigma changes cognitions.

The quality assessment tool that was used, and which resulted in two papers being disregarded was also problematic, and a potential limitation of the review. Each of the criterion included in the assessment tool was equally weighted, whereas some criteria such as controlling for confounders and the use of robust outcomes are arguably more important than criteria such as whether the research question is well defined. As a result the overall score it not necessarily reflective of the quality of the paper, thus making the decision to include or reject papers that scored around the threshold inaccurate. For example, it could be argued that the Rüsch et al. (2009) study ,which scored just below the threshold, was of higher quality than the Lee et al. (2011) study, which scored just above the threshold, as it controlled better for confounding factors and had more robust outcome measures. The potentially arbitrary cut-off of this tool, however, was judged to be necessary in order to make a comparisons between the cross-sectional and longitudinal studies included in this review.

Besides the potential difficulties with the quality tool that was adopted, the quality of the evidence presented in this review was good overall with 13 out of the 19 rated as of high quality. However, most of the studies only analysed the relationship between self-stigma and behaviour using correlations, and therefore beyond stating that there is relationship between the two factors it is not possible to understand the cause and effect of the relationship.

It is also important to consider how self-stigma was measured in these studies. The ISMI and the SSMIS both have good psychometric properties, and apart from one study (Adebayo et al., 2009) the measures were validated in their translated versions. However, both measures were developed in the US, and therefore it cannot be known whether cultural bias may affect how self-stigma is measured.

There was also a potential for bias in the selection of the studies for this review as due to practical reasons the database search, including the process of screening and deciding on the eligibility of the papers that were included was not double-checked by a second researcher. Also due to time restrictions it was not possible to contact all authors for additional information, such as establishing the effect sizes for different SEMs. Finally, the parameters of the search terms used were relatively narrow, and did not include research published in languages other than English, or in publications other than peer-reviewed journals.

Areas for further research

To develop a better understanding of the important relationship between self-stigma and behaviour there needs to be more research, and more focus is needed to behaviours beyond medication adherence to other behaviours that could impact on recovery. Furthermore, future research should seek to use more observational methods for measuring behaviour, or to triangulate self-reported information with recourse to other sources. More research which is longitudinal in design would also help in understanding how changes in self-stigma can affect behaviours, and the direction of the relationship.

More than half of the participants (57%) in this review were individuals with a diagnosis of schizophrenia. Fewer studies reported other SEMs separately and apart from two studies (Fung et al, 2007, 2008; Sarisoy et al., 2013), the studies that included individuals with different SEMs did not report the results separately. As a result, less is known about the relationship between self-stigma and behaviour in SEMs other than schizophrenia, and it is not necessarily the case that the results from individuals with schizophrenia can be generalised. Schizophrenia is a highly stigmatised mental health condition, and many of the stereotypes that exist about individuals with mental health problems, such as that they are dangerous and unpredictable, perhaps relate more closely to some subtypes of schizophrenia, than to other mental health conditions, such as depression and bipolar disorder (Angermeyer & Matschinger, 2003). The effect of both discrimination from others and reduced self-esteem, due to the application of negative stereotypes to oneself, could result in more behavioural changes in individuals with schizophrenia than those with other mental health conditions.

The ISMI was used in 13 of the 19 studies in the review but only three of the studies reported results for the different subscales (Hadja et al., 2015; Moriarty et al., 2011; Sedlackova et al., 2015). Based on the evidence of this review, alienation appears to be the most influential factor in medication adherence and perceived discrimination in social contact. It was not possible to identify how scores on the different ISMI subscales may relate to adherence with psychosocial treatments or employment. Further research that increases our understanding as to which elements of self-stigma are likely to have a significant impact on behaviour is important for the design of effective interventions.

This review suggests that reducing self-stigma should be a key part of the recovery process. Several interventions have been designed to help individuals resist self-stigma (for reviews see Mittal et al., 2012; Yanos et al., 2015). These interventions primarily consist of group interventions, and include elements of psycho-education, cognitive restructuring, narrative therapy, and behavioural activation. Their outcomes are mixed (Mittal et al., 2011) and they appear to be least effective for individuals with a diagnosis of schizophrenia. As more interventions are developed, it is important to ensure that interventions are well designed and target the right populations. In conclusion, more research is needed to gain a better understanding of the relationship between the different aspects of self-stigma and different behaviours which are likely to impede recovery, as well as the populations that are most likely to be affected by self-stigma and to benefit from interventions targeting it.

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Part 2: Empirical Paper

Measuring and conceptualising self-stigma and associated factors in people with intellectual disabilities

Abstract

Aim

Our understanding of self-stigma in people with intellectual disabilities (ID) is limited, in part due to the absence of a measure to use with the population. This study aimed to develop a new measure of self-stigma for use with people with ID and advance our understanding of how self-stigma relates to psychological distress and self-esteem as well as sociodemographic characteristics.

Method

A new 24-item measure consisting of items from established measures and newly developed items was designed with input from people with ID, academics and clinicians. Its five subscales measure self-stigma, self-esteem, psychological distress, reaction to stigma and sense of power. 135 participants with mild to moderate learning disabilities completed the measure; 21 of them of two separate occasions.

Results

The self-stigma subscale was not psychometrically sound. Data from the other subscales suggested that psychological distress was predicted by negative reaction to stigmatisation and gender, and that self-esteem related to sense of power.

Conclusion

The study found that if people with ID are aware of the negative attitudes that others have towards them this can lead to higher psychological distress. Further work is needed, however, to develop a measure of self-stigma in people with ID.

Introduction

Stigma can have a devastating impact on members of stigmatised groups, reducing the possibility of significant relationships, meaningful employment, and general well-being, which we might consider to be basic human rights. It can be experienced by any group or individual seen to deviate on a particular dimension from perceived social norms (Jahoda & Markova, 2004), permitting those with social, economic or political power to create a label that marks them as “different”. Once attached, these labels can consume an individual’s identity resulting in dehumanisation (Goffman, 1963), as well as loss of social status and self-esteem (Link & Phelan, 2001).

Attitudes towards individuals with intellectual disabilities (ID) have improved over recent decades but this group continues to be one of the most socially devalued and stigmatised groups. Comparative studies indicate that individuals with physical and sensory disabilities are far less stigmatised, and that only individuals with multiple disabilities or mental health problems are more stigmatised (Staniland, 2009; Yuker, 1998). Stigmatisation can be observed in the low levels of employment among individuals with ID, with only 7% of people with ID being in paid employment (Emerson et al. 2002), and high levels of bullying, with 9 out of 10 people with ID reporting verbal or physical abuse towards them (Mencap, 2000). Stigma can also reduce the likelihood of people with ID accessing healthcare and other services (Ali, King, Strydom & Hassiotis, 2015; Mencap, 2007,) and can be seen in more subtle ways of “benevolent prejudice” where people with ID are denied the opportunity to make decisions and experience over-protection from families (Jahoda, Wilson, Stalker & Cairney, 2010).

Self-stigmatisation

Self-stigmatisation occurs when labelled individuals are not only aware of stigmatising views others hold about their devalued attribute, referred to as public stigma, but also endorse such negative view or stereotypes (Corrigan, Kerr & Knudsen, 2005). This can lead to individuals applying the negative stereotype to themselves and changing behaviours accordingly (Corrigan, Watson & Barr, 2006). The subjective sense of being devalued can also lead to loss of self-esteem and self-efficacy, and prevent individuals from achieving life goals such as employment and relationships (Corrigan, Larson & Rüsch, 2009).

Given the multiple layers of social disadvantage that marginalised groups face, it can be hard to challenge stigmatising views held by others. However, research suggests some individuals are able to resist internalising negative stereotypes held about, or attributed to, a group (Sibitz, Unger, Woppmann, Zidek, Amering, 2011). Theoretical work (Campbell & Deacon, 2006) proposes that the process of resisting stigma can have the positive effect of empowering individuals resulting in them becoming “righteously angry” about stereotypes (Corrigan & Watson, 2002).

It appears that the extent to which people with ID self-stigmatise varies (Ali, Hassiotis, Strydom & King, 2012). In part this may be because not all individuals who are categorised as having ID are aware of this due to poor cognitive development, lack of self-awareness, over-protection by others or use of denial as a defence mechanism (Ali et al. 2012; Beart, Hardy & Buchan, 2005). Research on factors that may affect whether a person with ID internalises others' negative attitudes or into the consequences are of self-stigmatising is very limited to date.

While our understanding of factors associated with self-stigma is very limited in the ID field, self-stigma has been much more widely studied in the field of mental health, where research has identified a number of relationships between socio-demographic factors, psychosocial factors and self-stigma.

Psychosocial characteristics associated with self-stigma

Psychological distress – Psychological theory (Beck, 1987) would suggest that negative self and social evaluations lead to higher levels of psychological distress. This relationship has been observed in people with mental health problems, with symptom severity positively associated with self-stigma (Livingstone & Boyd, 2010). This association has also been shown in research in ID, where perceived stigma has been shown to contribute to higher levels of depression and anxiety in people with ID (Ali, King, Strydom & Hassiotis, 2015), and negative social comparisons have been associated with increased levels of depression (Dagnan & Sandhu, 1999; MacMahon & Jahoda, 2008).

Self-esteem – Self-esteem has consistently been shown to be negatively associated with the development and maintenance of psychological distress (Sowislo & Orth, 2013). Among people with mental health problems, those who internalise negative stereotypes are more likely to experience a loss of self-esteem and self-efficacy (Livingstone & Boyd, 2010; Ritsher, Otilingam & Grajales, 2003). This association between self-esteem and self-stigma is particularly strong when individuals agree with, and apply negative stereotypes to themselves (Corrigan, Watson & Barr, 2006). It has been hypothesised that low self-esteem and self-efficacy act as mediators between self-stigmatisation and the achievement of life-goals in areas such as housing, employment and relationships (Corrigan et al., 2009).

A relationship has been observed between self-esteem and psychological distress in the ID population (MacMahon & Jahoda, 2008). It has also been shown that people with ID who compare themselves negatively in terms of their achievements and competencies are likely to have lower self-esteem (Dagnan & Sandhu, 1999). The association between self-esteem and stigma or self-stigma has not, however, been investigated.

Sense of power – Self-stigma is negatively associated with a sense of power and mastery in people with mental health problems (Livingstone & Boyd, 2010; Ritsher et al., 2003). A sense of empowerment and belonging has also been observed to be an important factor in individuals being able to resist negative stereotypes from others (Corrigan & Watson, 2002). The relationship between sense of power and self-stigma has not been researched in people with ID.

Perceived stigma – Perceived stigma is the extent that individuals are aware of the prejudices of others. Although it has been hypothesised that being aware of stigma does not necessarily lead to an individual internalising and endorsing stigma, not unsurprisingly perceived stigma and self-stigma have been shown to be associated (Ritsher et al., 2003). Perceived stigma has also been shown to be associated with lower self-esteem and increased psychological distress (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001). Awareness of stigma has been shown to be associated with lower self-esteem in adolescents with ID (Szivos-Bach, 1993).

Socio-demographic characteristics associated with self-stigma

Age – There is evidence to suggest that older people with ID are likely to have higher levels of self-stigma than younger adults with ID (Ali et al., 2012). It was suggested that this could be due to cumulative life experiences, as well as living through an era when there was more discrimination and institutionalisation of people with intellectual disabilities. A review in mental health (Livingstone & Boyd, 2010) showed mixed results with significant associations found between higher self-stigma levels and being older but also associations between higher self-stigma and being younger.

Ethnicity – There is evidence to support the idea of "double discrimination", which hypothesises that individuals, with two or more stigmatising attributes such as ethnic minority status and ID or mental health problems, will face increased stigma (Gary, 2005). There is also evidence to suggest that attitudes to mental health problems vary between cultures (Angermeyer, Buyantugs, Kenzine & Matschinger, 2004), and that mental health problems are more stigmatised in cultures that are more collectivist (Hsu et al., 2008), which may in turn have an impact on self-stigma.

Education – Individuals with ID attending mainstreams schools are likely to feel more stigmatised than those attending segregated schools for students with special needs (Cooney, Jahoda, Gumley & Knott, 2006). However, this same study suggests that the experience of being stigmatised in school did not have an impact on future career aspirations or optimism for the future, suggesting that education may not affect self-stigma in the longer-term.

Living arrangements – Evidence suggests that individuals with ID can feel stigmatised when living at home, due to potentially being exposed to both criticism and over-protectiveness from their parents (Corker, 2013) and that living independently can be de-stigmatising (Jahoda & Markova, 2004). Jahoda and Markova's study also suggests that individuals can continue to feel stigmatised if they are living in supported accommodation or attending segregated day centres. Ali, King, Strydom and Hassiotis (2016) reported a trend towards an association between being married and having higher levels of self-stigma, a relationship that seems counter-intuitive as being in a relationship could be seen as being a normalising experience. This increased self-stigma may be due to criticism from partners (Corker, 2013)

Disabilities – Ali et al., (2016) reported a trend towards a relationship between physical health and additional disabilities, such as sensory, mobility and speech problems, and higher self-stigma in people with ID. As with ethnic minorities double discrimination has also been reported in people with ID and additional mental health problems or physical disabilities (Baum & Forchuck, 2008).

Existing measures of self-stigma

One of the barriers, to further developing our understanding of self-stigmatisation in people with ID, is a lack of a validated measure of self-stigma for use with this population. A systematic review (Werner, Corrigan, Ditchman & Sokol, 2012) highlighted a lack of scales available for measuring stigma and particularly self-stigma in the ID population. In their systematic review, Werner et al. (2012) reviewed 24 scales, five of which purported to measure self-stigma. They concluded that all of these self-stigma scales measured the degree to which individuals with ID perceive stigma rather than the extent to which they endorse stereotypes, apply these to themselves or change their behaviour as a consequence.

In the mental health field, there are two widely used measures of self-stigma: the Internalised Stigma in Mental Illness Scale (ISMI; Ritsher et al., 2003) and the Self-Stigma or Mental Illness Scale (SSMIS; Corrigan et al., 2006). The ISMI measures different constructs of self-stigma, reflected in its five subscales: Alienation measures a sense of being devalued by society; Social Withdrawal measures the extent to which the person is avoiding social contact; Stereotype Endorsement measures the extent to which people agree with prejudices held by others; Perceived Discrimination measures mistreatment which is attributed to the bias of others; and Stigma Resistance measures the extent to which a person can deflect stigma.

The SSMIS attempts to distinguish between perceived self-stigma, and other levels of self-stigma. To achieve this the scale consists of four subscales: Awareness, Agreement, Application and Harm. To complete the measure, respondents are given a stereotype about a person with a mental health problem and then asked to rate on a nine-point scale the extent to which they believe that the public think the stereotype is true (awareness), they personally believe the stereotype is true (agreement), apply the stereotype to themselves (application) and respect themselves less due to the stereotype (harm).

Developing measures for individuals with ID

Historically in the field of ID there has been a reliance on the use of proxy measures, informant reports and observations by researchers when trying to understand self-perceptions and self-understanding among this population. These methods have been adopted to avoid acquiescent responding and concerns about whether people with ID are reliably able to answer questions about self (Cuskelly, Moni, Lloyd & Jobling, 2013). However, it has been recognised that there is a need for this population to be able to voice their opinions more (Beart, Hardy & Buchan, 2004), and increasingly self-report measures are being used to understand the internal world of people with ID (Beail & Warden, 1996). A systematic review carried out by Vlissides, Beail and Golding (2016) of the outcome measures for psychological therapies found that some existing measures have been shown to be reliable for use with people with ID, but that it is often necessary to modify or develop new measures. The involvement of people with ID when developing or adapting measures, to ensure they are meaningful to this population, is an important part of this process (Brooks, Davies & Twigg, 2013).

As with any new measure a key part of the development is ensuring that a new measure is psychometrically-sound. This involves three steps: assessment of dimensionality, assessment of reliability and assessment of validity (Slavec & Drnovsek, 2012). Dimensionality refers to the number of common factors needed to account for the correlation among the items used in measure. This is usually assessed using exploratory factor analysis where there is no a priori hypothesis or confirmatory factor analysis, where there is an a priori hypothesis (Netemeyer et al., 2003). The second step, assessing the reliability of the measure, considers how much of the variance is due to the true score of the latent variable (De Vellis, 2003). This can be measured using a number of different tests including test-retest which ensures the stability of responses over time and internal consistency which ensures the homogeneity of items within a scale or subscale. The final step is establishing the validity of a new measure to ensure that a tool is measuring what it purports to measure. This can be assessed by the extent to which a measure corresponds with other theoretically relevant concepts. Reliability is a necessary precondition of validity (Nunally, 1978).

Rationale for the study

Despite self-stigma being central to our understanding of the distress caused by negative attitudes towards people with ID, there has been limited research in this area. A better conceptual understanding of self-stigma will help to establish whether it is solely public and structural stigma that prevents people with ID becoming fully integrated into communities, or whether self-stigma may also play a part in preventing them from reaching life goals such as applying for jobs, embarking on relationships, or making decisions for themselves.

A better understanding of self-stigma and associated factors may improve the development of interventions that seek to increase resistance to self-stigma and potentially reduce psychological distress. It may also help to ensure that any such interventions are offered to those most likely to find it difficult to resist stigma or to be distressed by others' negative attitudes and behaviours.

To progress the conceptual understanding of self-stigma it is important to establish whether it is possible to measure self-stigma in individuals with ID, in a way that differentiates perceived and internalised stigma.

Aims of the study

In order to improve our conceptual understanding of self-stigma the aims of this exploratory study were to:

1) Develop a psychometrically-sound measure of self-stigma suitable for use with people with mild to moderate ID.
2) Understand the relationship between self-stigma, psychological distress, low self-esteem and sense of power in people with ID.
3) Understand what sociodemographic characteristics can predict levels of self-stigma in people with ID.
4) Existing research would suggest that high levels of self-stigma, and low sense of power, would lead to higher levels of psychological distress and lower self-esteem. The final aim is to establish if this association exists in the ID population and the relative importance of psychosocial factors and sociodemographic characteristics in predicting levels of psychological distress and self-esteem

Methods

Participants

One hundred and sixty-two participants over the age of 16 with mild to moderate ID were recruited for the study and data was completed for 135 participants. For the purposes of this project a person was considered to be in the range of mild to moderate on the basis that they already (a) used services for people with intellectual disabilities, and (b) are engaged in language based groups, which require a level of communication skills that would be commensurate with mild to moderate intellectual disabilities. They were part of 21 existing groups run specifically for this population; nine groups, consisting of 81 participants were self-advocacy groups, ten were groups run by day centres consisting of 76 participants and one was a group at a college, consisting of five participants.

There was close to an even split between males and females, and the majority (54%) were under the age of 34. The majority were living with family members or in supported accommodation and two-thirds proportion had attended a “special school” at some point during their education. A fifth of the participants did not identify themselves as having an ID. Demographic and other relevant information is set out in Table 1 below.

Procedures

Ethical approval was granted from UCL Research Ethics Committee (Appendix 2). The recruitment strategy used convenience sampling and had two parts. Firstly, 10 groups consisting of 64 participants were recruited to take part in a study conducted in parallel, a feasibility study of an intervention (‘STORM’) aimed at helping individuals with ID to develop their capacity to resist self-stigma. These participants completed the newly developed measure prior to starting the programme. They were recruited through the Mencap network and through approaches to organisations known to work with people with ID in London and the South East of England.

Table 1 – Participant demographics (n=135)

	n	% (not including missing data)
Gender		
Male	67	54.5
Female	56	45.5
Missing data	12	-
Age		
16-24	26	20.2
25-34	43	33.3
35-44	28	21.7
45-54	17	13.2
55+	15	11.6
Missing data	6	-
Ethnicity		
White (any)	97	75.2
Black	16	12.4
Asian	7	5.4
Other	8	6.2
Missing data	7	-
Education		
Special needs school	81	64.3
Mainstream school	32	25.4
Both	13	10.3
Missing data	9	-
Living arrangements		
Living with family	75	58.1
Supported living	26	20.2
Living alone	13	10.1
Living with partner	11	8.5
Other	4	3.1
Missing data	6	-
Disability		
Self-declarative disability	110	81.5
Additional disability		
Autism	18	14.5
Physical disability	14	11.3
Sensory disability	13	10.5
>1 additional disability	28	22.6

A further 11 groups consisting of 96 participants, were recruited solely to complete the newly developed measure. Four of these groups had originally responded to the STORM recruitment, a further six were recruited through the Mencap network and other third sector organisations in the South East, and one group was recommended by a group already involved. Of the 96 participants recruited, valid responses were obtained data for 71 participants. Responses were considered invalid for the remaining 25 participants as items had been answered by either group facilitators or other participants, or there were concerns about whether the participant was able to comprehend the questions. In total data were collected for 135 individuals.

Contact was initially made with group facilitators to ascertain whether their members would be interested in taking part, either in the STORM project or in the present study. Information sheets were sent to group facilitators in advance of the session. This included information for the group facilitator (Appendix 3), for carers (Appendix 4) and an EasyRead version for group members (Appendix 5). Example items were also given to the group facilitators to ensure that the questions were suitable for the cognitive abilities of the group.

If there was agreement from the group, one to two members of the research team, depending on the size of the group, attended a group session to obtain consent (Appendix 6) and complete the measure (Appendix 7). During the session, the researcher read out the information sheet, giving individuals the opportunity to ask questions. The consent form was then read aloud and completed with the group and where it was indicated assistance was provided to individual group members to complete all items on the consent form. Once consent was gained, the researcher went through example questions such as “I like to watch sport on TV” to ensure that participants understood the response format. The researchers explained how they would answer the question using the response format available, emphasising that there was no right or wrong answer. The researcher then read through the paper items one by one with group members. This method has been shown to be effective when completing self-report measures with people with ID (Kellett, Beail, Newman & Mosley, 1999). Participants were asked not to discuss or share their answers.

Twenty-one participants from the groups that did not take part in the STORM project repeated the measure so that test-retest reliability could be assessed. The retest was carried out three to six weeks after the first test with administration procedures as described above.

All groups who took part in the STORM project received £100 toward their group budget to thank them for their input over seven study session. Groups who only completed the measure were entered into a prize draw to win £100.

Sample size

An a priori calculation was carried out to determine the sample size required to achieve 80% power with alpha set at 5% using G Power (Faul, Erdfelder, Lang, & Buchner, 2007). This indicated that in order to detect a moderate effect size in a linear regression analysis with and 12 predictors – socio-demographic (age, sex, ethnicity, education, living arrangements, awareness of ID and additional disability), self-esteem, psychological distress, negative reaction to stigmatisation and sense of power - a minimum sample size of 89 was required. A moderate effect size was chosen as this is reflective of the associations found between socio-demographic and psycho-social factors and stigma in a previous study with adults with ID (Ali et al., 2015).

Development of measure

To move beyond the current measures of self-stigma a new measure was seeking to assess not only how the participants felt about themselves and how they behave, but was also trying to understand how people with ID think about others with ID and how others might think about them as a result of their ID. Research has previously shown that reliability is poor when measures use abstract references (Cuskelly et al., 2013) and therefore the challenge in adapting and developing a new measure was to create questions which were significantly concrete to be meaningful to people with ID, while also encouraging them to think beyond whether they are aware of stigma.

The starting point was to look at the scales that are used with people with mental health problems, the ISMI (Ritsher et al., 2003) and the SSMIS (Corrigan et al., 2006). The ISMI is the more widely used measure, however, there were some concerns with using the measure. Firstly, the stigma resistance subscale which was felt to be a key part of the measure has poor reliability. Secondly, there were problems with the social withdrawal subscale as it relates to changes in behaviour after the onset of a mental health problem which is not relevant when thinking about a lifelong condition. Consequently, the decision was taken to use an adapted version of the SSMIS.

The SSMIS requires respondents to rate the extent that they agree with a given stereotype about a person with mental health problems. The decision on which stereotypes to include in the adapted version of the self-stigma measure was based on the literature of people with ID (May & Stone, 2010; Scior & Werner, 2015). Three broad stereotypes about people with ID were thought to be important: their inability to live independently, their inability to achieve their life goals, and their inability to form meaningful relationships. From these broad categories three statements were chosen relating to achievements, decision making and intimate relationships.

In addition to items measuring self-stigma, the questionnaire also included items intended to measure other psychosocial factors that had be observed to be associated with self-stigma in people with mental health problems (Livingstone & Boyd, 2010; Ritsher et al., 2003). These were included in order to further our understanding of self-stigma in people with ID, and establish whether the same associated factors predicted self-stigma in people with ID as in people with mental health problems, as well as to establish the construct validity of the new self-stigma items. These subscales were developed drawing on existing measures (Ali et al., 2008; Anderson, John & Keltner, 2012; Dagnan & Sandhu, 1999; Brooks, Davies & Twigg, 2013).

A Likert-type response scale was used based on evidence that such scales can produce reliable and valid responses when used with the ID population, and can reduce the acquiescence in comparison to using yes/ no responses (Fang et al., 2011; Hartley & MacLean, 2006). In deciding on the response scales we were trying to find the right balance between detecting change in self-stigma and therefore having more response options, while keeping the response options meaningful. Research suggests that a three-point response format is more reliable than a five-point format when used with people with ID (Fang et al., 2011) but a review of other measures adapted and created for people with ID, concluded that the response formats varied between two and five response options (Appendix 8).

All the existing measures that were drawn on used Likert-type scales but had different response items, varying between two and five options. The decision was taken to use the same four response options for each of the subscales - never, sometimes, often and always - apart from the items measuring self-stigma where the options were never true, sometimes true, often true and always true. Different response items were used for the self-stigma subscale as the items were asking participants about the beliefs they hold rather than the frequency of their behaviour or feelings. It was felt that these options would effectively measure change, while keeping the questionnaire simple to complete.

Content and face validity of the new self-stigma scale were assessed by sharing the questionnaire with a focus group of self-advocates with ID, as well as clinicians and academics working in the field. Following their input, the draft questionnaire was piloted with two groups with a total of 10 participants with mixed abilities within the mild to moderate range. Feedback from the pilot groups raised issues about feasibility and comprehensibility. These are outlined below, along with the changes that were made to address the issues raised.

Difficulties identified during piloting

A number of issues were raised about the comprehensibility of questionnaire items, both in regards to items taken from existing measures and the new self-stigma items. The first issue concerned negatively worded questions. Measures often have questions phrased negatively and positively in order to prevent acquiescence. However, feedback from our panel of experts and the pilot groups was that the negatively worded questions were hard to understand, such as "I feel that I haven't done anything worthwhile" in the self-esteem subscale, and the decision was therefore taken to only include positively phrased items, which resulted in removing the question from the self-esteem subscale. The exception was the question in the self-stigma measure that asked about relationships. It was felt that asking participants whether they think they or others with ID *should* have intimate relationships was very different from asking whether they think they or others with ID *should not* have relationship. The latter phrasing taps into existing prejudice that people with ID should not have intimate relationships, which is not achieved in phrasing this question positively.

The second comprehensibility issue related to the self-stigma measures, specifically questions that assessed participants' awareness of prejudices held by others, such as "Other people believe that someone with a learning disability should let others make decisions for them". Pilot participants struggled to identify what other people might be thinking, and in discussing the questions with them it became apparent that they had answered the questions from a first person perspective. Therefore the decision was taken only to measure the agreement and application constructs. Finally, participants in the pilot groups found some words difficult to understand, this included words such as 'ethnicity' and 'worthwhile'. In these cases the wording was changed in line with recommendations from the group, or if not possible the question was removed.

Beyond the comprehensibility of the questionnaire, there were two issues raised about the feasibility, the first of which was the negative emotions it evoked. The issue of self-stigma is emotive, and it was expected that participants completing the questionnaire might experience some negative emotions. Both groups, however, found one of the items measuring self-esteem - "At times I think I am no good at all' - very negative and this item was removed. Secondly there were issues with the length of the questionnaire as when the full draft measure was completed with the pilot group it was taking up to an hour to complete. The changes made to address comprehensibility went some way to reducing the length of the questionnaire, but in addition further questions were removed where it was felt by experts and participants that two questions were very similar. This resulted in the sense of power scale and psychological distress scale having a number of items removed. In total the questionnaire was reduced from 38 items to 24 items.

Finally the self-advocates and pilot groups provided helpful feedback on the response options. Hartley and Maclean's review (2006) how the presentation of response options may affect response rates. They concluded that response rates were higher when the answers were a set of single or two-word responses to questions rather than descriptive statements, and when there was some pictorial information. The focus group, self-advocates were shown different response options, which included numerical responses, pictorial options using blocks of increasing size to represent response options, and word responses. The agreement was that word responses with tick boxes was the clearest option.

There was feedback that the participants were not able to differentiate between "sometimes" and "often", and therefore in the final version the "often" response option was removed in all the scales. In the self-stigma the options, were no, sometimes and yes and the for the rest of the items the response options were never, sometimes and always. The items were also rearranged so that all the subscales that used the never, sometimes, always response items were asked sequentially and the participants did not have to move between using the two different response options.

Final measure

The final measure, called the "Myself and the World' questionnaire for the purpose of the study, was a composite of items taken from existing measures and items newly developed for this study (Table 2). It had 24 items with five subscales, measuring self-esteem, psychological distress, negative reaction to stigmatisation, sense of power and self-stigma. Additional questions relating to sex, age, educational background, ethnicity, living arrangements, self-perceived disability status and additional disabilities were asked.

Self-esteem (items 1-3) - Rosenberg's Self-Esteem (RSE) scale (1979) has been adapted for use with individuals with ID (Dagnan & Sandhu, 1999). The adapted version has six items of which four are positively and two are negatively worded, and uses a four-item response scale. It has acceptable psychometric properties with a Cronbach's alpha of 0.62 reported in Dagnan and Sandhu's (1999) original study. Test-retest reliability was not reported in the original paper, but in a later study (MacMahon & Jahoda, 2008) a Pearson correlation of 0.68 was reported.

Doubts have been raised about the reliability and validity of some items when using this RSE with people with ID both in the full version and the adapted version (Davis, Kellett & Beail, 2009). These items were omitted from the present measure, along with questions phrased negatively. A three-item subscale was used in this study. Higher scores represent higher levels of self-esteem

Negative reaction to stigmatisation (items 4-7) **-** An adapted version of the Perceived Stigma scale for individuals with ID (Ali et al., 2008) was used. The original scale consists of 11 questions, which measure experiences of discrimination and reaction to discrimination. The experiences of discrimination subscale describes negative treatment and discrimination experienced, such as "people look down on me". The "reaction to discrimination" subscale assesses how people feel in response to discrimination, such as "people make me feel embarrassed".

In the study, participants only completed three of the four items measuring their reaction to discrimination. It was felt that these items measure some of the cognitive aspects of self-stigma and an ability to resist self-stigma, although it was not assessing whether individuals were internalising prejudices. The original measure has good psychometric properties; the Cronbach's alpha for the whole scale was 0.84, and 0.69 for the reaction to discrimination subscale in Ali et al. (2008) study. The test re-test reliability had a kappa co-efficient of 0.71 representing substantial agreement. Higher scores represent more negative reactions to stigma.

One item (item 4) was added, to assess whether individuals attempt to conceal their disabilities from others in reaction to the stigma they experience.

Sense of power (items 8-11) **-** An adapted version of the eight-item Sense of Power scale (Anderson et al., 2012) was developed to assess participants' personal sense of power. The number of questions was reduced to four, and the language was simplified from the original version. All the items were phrased positively, whereas in the original version half were positively and half negatively phrased. The original version of the measure has good internal reliability with Cronbach alphas ranging between 0.82 and 0.85 (Anderson et al., 2012). Higher scores represent higher levels of empowerment

Psychological distress (items 12-18) **-** A shortened 7-item version of the 14-item Clinical Outcome for Routine Evaluation for people with ID (CORE-LD) (Brooks et al., 2013) was used to measure psychological distress. The CORE-LD is an adapted version of the CORE-OM. The measure is psychometrically-sound with a Cronbach's alpha of 0.80 and with good test-retest reliability (p=0.64) in both clinical and non-clinical individuals (Brooks et al., 2013). The CORE-LD was designed to be given to individuals who access mental health services. As the present study used a community, not a clinical sample, and a group setting, in discussion with the ethics committee it was deemed not appropriate to include two items asking about self-harm and suicidal ideation. Higher scores represent higher levels of psychological distress.

Self-Stigma (items 19-24) - The new self-stigma measure was developed based on the SSMIS (Corrigan et al., 2006). The measure was shortened, only measuring agreement with, and application to self of negative stereotypes. The number of statements was also reduced to three, which related to achievements, decision-making and intimate relationships.

Table 2 – Myself and the World Measure

Self-esteem		
1.	I feel that I have a lot of good qualities	Never, Sometimes, Always
2.	I am able to do things as well as other people	Never, Sometimes, Always
3.	I like myself	Never, Sometimes, Always
Negative reaction to stigmatisation		
4.	I try to hide my learning disability	Never, Sometimes, Always
5.	The way people talk to me makes me angry	Never, Sometimes, Always
6.	People make me feel embarrassed	Never, Sometimes, Always
7.	I keep away from other people because they are not nice to me	Never, Sometimes, Always
Sense of power		
8.	I can get other people to listen to me	Never, Sometimes, Always
9.	I can get others to do what I want	Never, Sometimes, Always
10.	I get to make decisions	Never, Sometimes, Always
11.	Others pay attention to my views	Never, Sometimes, Always
Psychological distress		
12.	Have you felt really lonely	Never, Sometimes, Always
13.	Have you had difficulty getting to sleep or staying asleep	Never, Sometimes, Always
14.	Have you threatened or shouted at someone	Never, Sometimes, Always
15.	Have you felt unhappy	Never, Sometimes, Always
16.	Have you felt people are getting at you	Never, Sometimes, Always
17.	Have you bottled up angry feelings	Never, Sometimes, Always
18.	Have you felt really scared or frightened	Never, Sometimes, Always
Self-stigma		
19.	I think most people with learning disabilities will achieve very little in life	Yes, Sometimes, No
20.	I think most people with learning disabilities should let others make decisions for them	Yes, Sometimes, No
21.	I think most people with learning disabilities shouldn’t have romantic relationships	Yes, Sometimes, No
22.	Because I have a learning disability I don’t try to achieve things	Yes, Sometimes, No
23.	Because I have a learning disability I let others make decisions	Yes, Sometimes, No
24.	Because I have a learning disability I shouldn’t have romantic relationships	Yes, Sometimes, No

Data analysis

The data were analysed using SPSS version 24. The scale's and subscales' psychometrics properties were first tested using Cronbach's alpha and Kappa coefficients. A decisions was taken not to assess the dimensionality of the self-stigma subscale, as it was assumed that the construct of self-stigma that had been well established in the mental health field would also exist in the ID population. A correlation was conducted to investigate the relationship between the different psychosocial factors, and t-tests and ANOVAs were used to look at the relationship between socio-demographic characteristics and self-stigma and factors associated with it. A multiple regression was run to look at the relationship between those factors that were found to have significant associations with psychological distress and self-esteem at the first stages of analysis.

There was data missing for 18 participants; Little MCARs test showed that the data was missing at random (χ^2 (538, N=135) = 510.99, $p = 0.79$). Pairwise comparisons were used for t-tests, ANOVAs and correlations. Listwise comparisons were used for the regression analysis.

Joint project

This was a joint project with Kristina Fenn, who was looking at the feasibility of the STORM project (Fenn, 2018) as outlined above. An outline of the individual contributions is included in Appendix 10.

Results

Psychometric properties of the measure

The first aim of the study was to develop a psychometrically sound measure of self-stigma in people with ID. In addition to testing the psychometric properties of the newly developed items, the reliability of the measures that had been adapted to assess self-esteem, psychological distress, negative reaction to stigmatisation and sense of power was also examined.

Internal consistency

The internal consistency of the subscales was assessed using Cronbach's alpha (Table 3); the α values for the different subscales were between 0.59 and 0.77 indicating fair to acceptable reliability. Acceptable Cronbach's alpha values are deemed to be greater than 0.7 (Kline, 1999), but in the early stages of research it has been suggested that values down to 0.5 are acceptable (Nunally, 1978). However, as the value of α is dependent on the number of questions, with fewer questions resulting in lower α values (Cortina, 1993), the decision in this study to reduce the number of questions in each subscale for feasibility reasons is likely to have resulted in lower values of α.

The analysis showed that the α for negative reaction to stigmatisation subscale increased when the additional question which asked about individual's tendency to hide their disability was not included. Thereafter this additional item was analysed separately as 'concealment of disability'. The analysis also showed an increased α for the psychological distress subscale when the item 14 asking about whether individuals had felt threatened was deleted. In further analysis this item was therefore not included in the subscale.

Test-retest reliability

The test-retest reliability of the new self-stigma subscale and the adapted measures was assessed using Kappa co-efficient (Table 3). This statistic is recommended rather than an interclass correlation when the data are categorical or nominal (Landis & Koch, 1977). Test-retest was not examined for the psychological distress subscale, as these items refer to how the individual has felt "over the previous week" and therefore changes in an individual's responses may be due to changes in mood rather than the reliability of the measure.

Self-esteem, negative reaction to stigmatisation and concealment of disability had coefficients between 0.23 and 0.33 which indicate 'fair' agreement (Landis & Koch, 1977). However, the sense of power and the new self-stigma scale had zero agreement. In the self-stigma scale, the only item that was shown to have fair agreement was item 23 (Table 2), which asked participants if they let others make decisions for them. Based on this, the decision was taken not to include the new self-stigma scale in any further analysis as it was not considered to be reliable. The decision was also taken not to test the validity of the new subscale. However, the sense of power subscale was included in further analysis, as although the overall measure had poor test retest reliability, two of the four questions had "fair" agreement (.38 and .40).

The low test-retest scores could have resulted from the administration method used. The original measures were designed to be completed individually, whereas in this study the questionnaire was completed in groups varying in size between four and thirteen participants. It could also have been due to reducing the number of items in each subscale, and changing the response items. Previous studies showed higher test-retest reliability of both the adapted RSE measure (*r* = 0.68) (MacMahon & Jahoda, 2008) and the Perceived Stigma measure (kappa = 0.71) (Ali et al., 2008).

Table 3 – Cronbach's alpha, Cohen's kappa co-efficient, mean score and standard deviation for subscales

	Cronbach's α	Cohen's Kappa co-efficient	Mean	SD
Self-esteem (n=124)	.60	.23	4.35	1.33
Psychological distress (n=127)	.65	n/a	4.96	2.59
Psychological distress$*$ (n=128)	.66	n/a	4.55	2.43
Negative reaction to stigmatisation (n=130	.60	.33	2.88	1.43
Concealment of disability (n=134)	n/a	.29	0.84	0.79
Sense of power (n=124	.61	.00	5.17	1.70
Self-stigma (n=126)	0.59	.00	3.32	2.53

$*$ Psychological distress scale without item 14

The psychometric analysis raised issues about the extent to which the questionnaire was a psychometrically-sound measure, and as a result conclusions from this study should be treated with caution. The potential problems which could have resulted in the poor internal consistency and test re-test reliability have been discussed, and it will be important that further research looks at the best ways to measure these concepts in people with ID.

Normality

The data were tested for skew and kurtosis to ensure normality prior to further analyses. Z-scores were calculated for each of the subscales and normality was tested at $p = 0.1$, $z = 2.5$. The self-esteem, psychological distress, negative reaction to stigmatisation and sense of power subscales did not show significant skew or kurtosis. The concealment of disability question tested significantly for kurtosis ($z = 2.89$) and therefore non-parametric statistics were used on this subscale.

Relationship between psychosocial variables

The second aim of the study was to understand the relationship between the psychosocial variables. As noted in the Introduction self-stigma, self-esteem, psychological distress, negative reaction to stigma and sense of power have been shown to be related to one another. Although it was not possible to measure self-stigma, the relationship between the other psychosocial variables was examined using a Pearson's and Spearman's rho correlation. A Bonferroni correction adjusted alpha of 0.005 (0.05/10) was used, as there were 10 comparisons being made.

A positive relationship was found between self-esteem and sense of power, (Table 4), with increased sense of power associated with higher levels of self-esteem. There was, however, no relationship between self-esteem and psychological distress, negative reaction to stigmatisation or concealment of disability.

Table 4 - Correlations between psychosocial variables (n=110)

	1	2	3	4	5
1.Self-esteem	-	r_p=-.07 *p*=.45 [-0.24,0.09]	r_p=.05 *p*=.58 [-0.12,0.23]	r_p=.42** *p*<0.001 [0.21,0.6]	r_s=.01 *p*=.59 [-0.12,0.22]
2.Psychological distress		-	r_p=.41** *p*<0.001 [0.25,0.56]	r_p=-.25* *p*=.009 [-0.41,-0.1]	r_s=.04 *p*=.
3.Negative reaction to stigmatisation			-	r_p=-.03 *p*=.78 [-0.25,0.18]	r_s=.05 *p*=.59 [-0.16,0.25]
4.Sense of power				-	r_s=.12 *p*=.13 [-0.05,0.33]
5.Concealment of disability					-

**p*<.05*,* ***p*<.005 (Bonferroni correction), BCa bootstrap 95% CIs reported in brackets

Significant relationships were found between psychological distress and both negative reaction to stigmatisation and sense of power (Table 4). Increased psychological distress was related to more negative reaction to stigmatisation and reduced sense of power. The relationship between psychological distress and sense of power was no longer significant after Bonferroni correction.

There was no association between negative reaction to stigmatisation and sense of power, and concealment of disability was not shown to be related to any of the other psychosocial variables.

Sociodemographic characteristics

The third aim of the study was to further our understanding of self-stigma in people with ID by assessing whether any sociodemographic characteristics are associated with more negative self-perceptions. In the absence of psychometrically-sound measure of self-stigma, the association of sociodemographic characteristics with self-esteem, psychological distress, sense of power and negative reaction to stigmatisation was assessed. As noted, previous research has shown all these factors to be related to self-stigma. As concealment of disability was not shown to be associated with the other psychosocial factors in the preceding analyses, it was not included in this part of the analysis.

The relationships were determined using Independent t-tests and one-way ANOVAs (Table 5). To avoid type 1 errors resulting from multiple hypothesis testing, a Bonferroni correction to $p<.001$ (.05/35) was used as there were 35 comparisons being made.

Gender was found to be associated with psychological distress suggesting that females are more likely to have higher levels of psychological distress (*M* = 5.41, *SD* = 2.39) than males (*M* = 3.72, *SD* = 2.20), with a medium to large effect size. In further analyses gender predicted 12% of the variance seen in psychological distress ($R^2 = 0.12$ $F(1,116)=15.94$, $p<0.001$). Gender was also found to be associated with negative reaction to stigmatisation, with females reporting more negative reaction to stigma (*M* = 3.22, *SD* = 1.53) than males (*M* = 2.63, *SD* = 1.36), with a small effect size but this was not significant after Bonferroni correction.

Age was found to be associated with self-esteem with a small effect size but again this was not significant after Bonferroni correction. Although some small and medium effects size were observed, education, ethnicity, living arrangements, awareness of ID and additional disabilities were not found to be significantly related to self-esteem, psychological distress, negative reaction to stigma and sense of power.

Table 5 – Association between psychosocial factors and sociodemographic characteristics

	Self-esteem		Psychological distress		Negative reaction to stigmatisation		Sense of power	
	stats (df), _p_, [95% CI]	Effect size _d,_ [95% CI]	stats (df), _p_, [95% CI]	Effect size _d,_ [95% CI]	stats (df), _p_, [95% CI]	Effect size _d,_ [95% CI]	stats (df), _p_, [95% CI]	Effect size _d,_ [95% CI]
Gender	_t_(115) = 0.55 _p_=.58 [-0.35,0.62]	.10	t(116) = -3.99 _p_<.001** [0.36, 1.11]	.74	_t_(117) = -2.23 _p_=.03* [-1.11,-0.67]	.41	_t_(110) = 0.31 _p_=.76 [-0.55,0.76]	.06
Age	_F_(4,115) = 2.74, _p_=.03*	.62	_F_(4,118) = 0.53, _p_=.72	.25	_F_(4,120) = 0.72, _p_=.58	.31	_F_(4,113) = 1.22, _p_=.30	.42
Ethnicity	_t_(116) = -0.96 _p_=.34 [-0.91, 0.34]	.23	_t_(119) = -0.87 _p_=.39 [-1.49, 0.58]	.19	_t_(121) = -0.86 _p_=.39 [-0.86,0.34]	.18	_t_(115) = 0.51 _p_=.61 [-.055,0.93]	.11
Education	_F_(2,114) = 1.2 _p_=.31	.29	_F_(2,118) = 1.66 _p_=.94	.34	_F_(2,120) = 0.13, _p_=.88	.09	_F_(2,112) = 1.37, _p_=.26	.31
Living arrangement	_F_(4,116) = 0.33, _p_=.86	.21	_F_(4,119) = 0.57, _p_=.69	.28	_F_(4,121) = 0.57, _p_=.69	.27	_F_(4,114) = 0.84, _p_=.50	.35
Awareness of ID	_t_(115) = -0.54 _p_=.59 [-1.2,0.76]	.16	_t_(117) = 0.31 _p_=.76 [-.1.19,1.64]	.10	_t_(119) = -0.44 _p_=.64 [-1.03,0.65]	.15	_t_(112) = 0.63 _p_=.53 [-0.67, 1.3]	.19
Additional disability	_F_ 0.28 (5,111) _p_=.89	.20	_F_(5,113) = 0.76, _p_=.56	.33	_F_(5,115) = 0.05, _p_=.99	.08	_F_(5,108) = 1.53, _p_=.20	.40

*p<0.05, **_p_<0.001 (Bonferroni correction)

Predictors of psychological distress and self-esteem

The final stage of the analysis assessed whether negative reaction to stigmatisation and sense of power could predict levels of self-esteem or psychological distress, as shown in existing research in the mental health field, and the relative importance of sociodemographic characteristics and psychosocial factors in predicting self-esteem and psychological distress. The analysis showed that sense of power, which was the only variable found to be associated with self-esteem predicted 18% of the variance in self-esteem (R^2=0.18 F(1,111)=24.85, p<0.001). It was not predicted by any sociodemographic characteristics.

The previous analyses showed that psychological distress was related to reaction to stigmatisation and gender. These two factors were entered into a hierarchical regression (Table 6). Negative reaction to stigmatisation predicted 18% of the variance in psychological distress, and when gender was included in the model, a further 7% of variance in psychological distress was predicted,

Table 6 – Predictors of psychological distress: results of hierarchical regression (n=117)

	B (CI)	*SE B*	*β*	*p*
Step 1				
Constant	2.46 (1.65, 3.26)	0.43		0.001
Experienced stigma	0.70 (0.42, 1.01)	0.15	.42	0.001
Step 2				
Constant	0.83 (-0.43, 2.13)	0.67		0.24
Experienced stigma	0.61 (0.35, 0.89)	0.14	.36	0.001
Gender	1.31 (0.58, 2.07)	0.40	.27	0.002

Step 1 - R^2=0.18 F(1,115)=24.91, p<0.001
Step 2 - R^2=0.25 F(2,114)=18.69, p<0.001.

Discussion

Psychometric properties of the newly developed measure

Overall the results indicate that the adapted measure of self-stigma was not psychometrically sound, with only just acceptable levels of internal consistency and poor test-retest reliability. This poor reliability could be due to the wording of the questionnaire and/or the administration of the measure, both of which are discussed further below.

Observation of participants completing the measure, and feedback from participants and facilitators suggested that there were three difficulties with the measure which are likely to have affected its reliability. Firstly, participants found it difficult to answer questions phrased negatively. Secondly, they found it difficult to think about their own prejudices towards other people with ID separately from how they felt about themselves. Finally they found it hard to answer questions which were not about a specific behaviour or feeling. The only self-stigma subscale item which had fair test-retest reliability was item 23 (Table 2), which asked individuals about whether having an ID meant that they should let others make their decisions for them. This item was phrased positively and was perhaps more concrete as it was focused on a specific behaviour rather than the more vague concepts such as “achieving things”. It was also asked about participants’ own behaviour rather than their attitudes towards others.

These results point towards an number of issues that should be thought about in future attempts to measure self-stigma in people with ID. Firstly they suggest that assessing self-stigma in terms of awareness of, agreement with and application to self of negative stereotypes, as proposed by Corrigan et al. (2006) is too abstract for people with ID. There are also indications that future attempts to measure the construct should be based on more specific behaviours or feelings that people with ID have about themselves. Although the decision was taken not to adapt the ISMI (Ritsher et al., 2003) because of the problems with two of the subscales, there are individual items that focus on specific feelings and behaviours that could be considered, such as “feeling as though I am treated as a child”. The feedback also suggests that it is important that any future measure should avoid negatively phrased questions such as “I shouldn’t get married”. This, however, does raise issues as many negative stereotypes about people with ID relate to what they cannot do; consequently it is important to understand what people with ID may not do because of self-stigma. Further work with people with ID needs to be done to think about more acceptable phrasing, and more broadly how to access self-stigmatising attitudes they may hold.

In addition to the poor reliability of the self-stigma subscale, the decision to use a measure designed for people with mental health difficulties without testing its dimensionality using exploratory factor analysis or confirmatory factor analysis was problematic. In the absence of this it was not possible to establish if a common factor or factors could account for the correlation among the items in the self-stigma scale and therefore to confirm whether self-stigma exists as a latent variable in people with ID, as hypothesised in mental health research.

While it is important to think about how self-stigma can be measured in people with ID and how to involve this population is designing a new measure, it is also important to acknowledge the conclusion that it is not possible to measure this construct using a quantitative methodology. The findings of this study may suggest that qualitative and ethnographic approaches should be adopted by researchers investigating self-stigma in people with ID.

Beyond, looking at the items that were included in the measure to assess self-stigma, it is also important to think about how items taken from measures were adapted or further adapted for this population and how this could have affected their reliability. In an attempt to balance the feasibility of participants being able to complete the questionnaire and trying to measure a number of different psychosocial factors, each of the measure had items removed. The reduced number of items will have affected the internal consistency (Cortina, 1993), however, it is not known whether the items that were removed would also have increased test-retest reliability. This brings into question the optimum way of carrying out research with people with ID. It was clear from the study that participants were not able to concentrate for more than 30 minutes and therefore it may have been preferable to investigate fewer factors or carry out the assessment over more than one sitting, rather than try and assess more factors across fewer questions.

As noted previously the poor reliability in both the items measuring self-stigma and the other subscales could also have been due to the conditions under which the measures were completed. The data were collected in groups rather than individually to reduce the time and resources needed. Although each group had at least one researcher and one facilitator to assist participants, and in many groups significantly more because of the larger size, the responses may have been more reliable if participants had received one-to-one assistance from a researcher in completing the measure. We took significant steps to support participants in the group format as would have been used if the measure had been administered individually such as, moving at their pace, offering reassurance, stressing that there were no right or wrong answers and clarifying meaning of unfamiliar words. However, in other studies where these or similar measures have been used (Ali et al., 2015; Dagnan & Sandhu, 1999; MacMohan & Jahoda, 2004) they were administered individually.

Relationship between psychosocial factors

In the interpretation of the relationship between psychosocial factors, as well as the other interpretations, it is necessary to acknowledge that the measures that were used to assess self-esteem, psychological distress, sense of power and negative reaction to stigmatisation, were adapted versions of the validated measures, with wording simplified and items omitted in the measures. None of the adapted measures had good reliability and the sense of power scale overall had no agreement although there were two items which had fair agreement. As previously mentioned this could have been due to the items being removed or the administration of the measures. In light of this, all the conclusions drawn should be treated with caution.

The analysis explored the relationship between self-esteem, psychological distress, negative reaction to stigmatisation, sense of power and concealment of disability. The results showed that there was a relationship between negative reaction to stigmatisation and psychological distress, with negative reaction to stigmatisation explaining 18% of the variance in psychological distress. This replicates the findings of Ali et al. study (2015), which was also carried out with a non-clinical population, and shows that there is an association between individuals being aware of negative attitudes that others have towards them and higher psychological distress, regardless of whether they internalise negative attitudes. The findings are also consistent with research with people with mental health problems. The analysis also showed a trend in relationship between sense of power and psychological distress, with lower levels of sense of power associated with greater psychological distress. If a higher sense of power is thought to relate to an increased ability to resist stigma (Corrigan, 2002) it follows logically, given the relationship between psychological distress and negative reaction to stigmatisation, that there is an association between sense of power and psychological distress.

The analysis also showed that sense of power predicted 18% of the variance in self-esteem, with a higher sense of power predicting higher self-esteem. This could suggest that if individuals with ID have a greater sense of control and mastery over their lives and decisions, this is likely to lead to higher self-esteem. Alternatively, it could indicate that people with ID who have a higher sense of self-esteem are likely to feel more confident to take control over their lives and decisions. This finding relates to earlier findings that individuals with ID who compare themselves negatively to others with regards to their mastery have lower self-esteem (Dagnan & Sandhu, 1999).

Of note, there was no relationship between self-esteem and negative reaction to stigma. The lack of relationship between these two factors could be due to only measuring self-stigma at the level of awareness and not at the level of agreement and application. Corrigan et al. (2006) found no association between an individual's level of self-esteem and their awareness of stigma in people with mental health problems. The lack of association may also relate to the righteous anger that some individuals feel when they are aware of negative stereotypes, which can result in them feeling empowered (Corrigan, 2002). This can be observed in self-advocacy groups for people with ID, where one might argue that an increased sense of power supports the development of sense of righteous anger and mobilises its members to advocate on behalf of other people with ID to oppose discrimination.

The hypothesis that being aware of prejudice can lead to an increased sense of power may also help to explain the absence of a relationship between negative reaction to stigmatisation and sense of power. Some individuals may feel empowered in response to prejudice but for others awareness of negative attitudes held by others may have a deleterious impact on their well-being in turn resulting in a reduced sense of power and mastery.

The present study found that there was no relationship between self-esteem and psychological distress. This runs counter to previous research with people with ID in both clinical and non-clinical settings (Dagnan & Sandhu, 1999; MacMahon & Jahoda, 2008). It is also a very well established relationship in the field of mental health (Swislo & Orth, 2013). The lack of relationship between these two factors could be as a result of issues of the measurements used for self-esteem and psychological distress, and their poor psychometric features, as previously discussed.

No relationship was observed between concealment of ID and the other psychosocial factors. It was hypothesised that a person's decision to conceal their ID would be related to their negative reaction to stigmatisation. However, the psychometric analysis suggested that concealment of disability was not measuring the same construct as negative reaction to stigmatisation. The absence of an association between this item and any other psychosocial factor assessed, could suggest that an individual may conceal their ID to achieve both positive and negative outcomes. The decision to conceal or disclose a devalued trait is complex; for people with concealable stigma, deciding not to disclose can result in psychological distress (Pachankis, 2007), however, while disclosure can increase available support and improve well-being, making a decision to reveal in the absence of a supportive network can also result in further stigma (Chaudoir & Fisher, 2010).

Some people might choose to hide their ID for fear of negative responses leading to psychological distress, while for others successful concealment may result in increased self-esteem and empowerment. Alternatively, the concealment of their ID may not be an option for some, or acknowledging it may be an essential step in seeking support or securing acceptance (Connolly, Williams & Scior, 2013). These results should be interpreted with caution though as there was only one question on concealment which showed only fair test-retest reliability. Further research should consider what concealing ID may mean to people with ID.

The role of sociodemographic characteristic

The study explored the association between gender, age, ethnicity, education, living arrangements, awareness of intellectual disability and additional disability and the psychosocial factors. Higher psychological distress was seen in females, with gender predicting 7% of the variance seen in psychological distress beyond the 18% that was explained by other psychosocial factors. Surveys have consistently shown that women are more likely to experience common mental health disorders than men (Adult Psychiatric Morbidity Survey, 2014), although the relationship between gender and common mental health problems in people with ID is not consistent (Axmon, Sandberg & Ahlström, 2017). Some research has shown that depressive symptoms are more prevalent in women (Lunsky, 2003), while others have not found any differences in the prevalence of anxiety and depression in men and women with ID (Cooper et al., 2007; Tsakanikos, Bouras, Sturmey & Holt, 2006). The results from this study would suggest that people with ID are reflective of the general population, with women experiencing higher levels of psychological distress, although the measure used in the current study assessed psychological distress and was not a diagnostic or screening tool for mental health disorders such as depression or anxiety.

No relationship was found between age, type of education, living arrangements, ethnicity, and any of the psychosocial factors counter to the findings in previous research with people with ID (Ali et al., 2012; Cooney et al., 2006; Gary, 2005; Jahoda & Markova, 2004). Finally although no association was seen between awareness of ID and any of the psychosocial factors, the findings did suggest that not all the participants - who were all considered to have ID because they were participating in groups established specifically for people with ID - acknowledged the label of intellectual disability. This finding is consistent with findings by Finlay and Lyons (1998). Crabtree, Mandy and Mustard (2017) suggest that the acknowledgement of belonging to a group can reduce stigmatisation because of the availability of shared group identity to reject stigma and the decreased likelihood of making out-group comparisons which has been observed to decrease self-esteem (Jahoda & Markova, 2004). It is therefore potentially of concern that a fifth of the participants do not acknowledge the label of ID, and this may be resulting in increased self-stigma.

Limitations of the research

There were considerable limitations in this research due to the poor reliability of the measure used. As discussed previously, this could be due to difficulties in the administration of the measure rather than it being an inherent problem with the measure, but it may also indicate that questionnaires are not a suitable tool to use to measure self-stigma in people with ID. Researchers might want to consider using other mediums such as pictures or short video clips to try and understand the views of participants.

Further research should ensure that the measure is completed in smaller groups, so that there is more assistance available for those participants completing the questionnaire, but also more oversight to ensure comprehensibility and reduce the chance of participants being influenced by others. Consideration should also be given to using more concrete examples and focusing only on how individuals apply prejudices towards themselves as opposed to whether they aware of, or agree with existing prejudices held by others.

The poor psychometric properties may also, however, have arisen as a result of adapting a scale that had been developed for people with mental health difficulties rather than developing a new scale specifically for people with ID. If more time had been available a preferable way to develop a new measure of self-stigma would have been to employ qualitative research techniques. This could have included focus groups or face-to-face interviews with people with ID, as well as their carers and families, to get a better understanding of what self-stigma means to people in this population and to have established common stereotypes that exist for this population. An alternative approach, used by Brooks, Davies and Twigg (2013) in developing the Clinical Outcome for Routine Evaluation for people with ID measure (CORE-LD), would be to set up a research group including people with ID, who would form an integral part of the research team and be heavily involved in designing the items in the measure.

The inclusion criteria for participants was also likely to have been problematic. Although there was no test carried out to assess the cognitive abilities of the participants it was clear from attending the groups that there was a wide variation in the cognitive abilities of those completing the measure. This is problematic as the construct of self-stigma may vary depending on the cognitive abilities of an individual (Ali et al., 2012). In addition, a language-based approach might be more suitable for individuals with mild ID (Hartley & Maclean, 2006). In future development it could be more appropriate in the first instance to develop a scale which was aimed specifically at individuals with a mild ID, who are potentially more aware of the negative stereotypes that exist.

In addition to the issues with the inclusion criteria for the participants, the use of a convenience sample also introduced some potential bias. The participants came from different settings - self-advocacy groups, day centres and one college – but participation in these groups is through self-selection either because they choose to act as a self-advocate or choose to attend day centres or college, and therefore it might be that group members (particularly those in the self-advocacy groups) feel more empowered and potentially better able to resist stigma than people with ID in the general population. It is perhaps those who do not choose to partake in such groups for whom self-stigma is particularly problematic. It could also be that the group facilitators who volunteered to take part in research relating to stigma are already discussing stigma with members and encouraging them to feel empowered. Again this is not necessarily an experience that all people with ID will have when attending day centres and colleges.

In order to manage resource limitations, this study was only conducted in the South East of England and therefore the findings are not necessarily representative of individuals throughout the UK. The participants were predominantly white (75%) and existing research suggests that individuals from other ethnicities are likely to experience higher levels of stigma, as a result of double discrimination (Gary, 2005), and different cultural attitudes (Scior, Potts & Furnham, 2013). Further research should look to access a more representative sample, as again there is a possibility this sample experienced different levels and types of prejudice than people with ID in the general population. This potential bias, as well as the self-selecting nature of the participants, mean that is not possible to generalise the results to the wider population.

Clinical and research implications

This study highlights the difficulty of using self-report measures with people with ID. Although there is evidence to suggest that self-report measures can be used reliably with people with ID, the psychometric analysis from this study shows caution needs to be exercised when measures are adapted and administered. The results suggest that adapted measures need to be concrete to ensure comprehensibility, and that care needs to be taken in the administration of self-report questionnaires. It would be a backward step to suggest that researchers should not continue to develop measures specifically for this population. The involvement of people with ID earlier on in the development of the measure could have improved the comprehensibility and feasibility of the measure, and potentially have increased its reliability. However, it is also important to acknowledge poor test-retest results show that maybe people with ID are fairly inconsistent with their own attitudes, and that researchers should look at other methodologies to assess attitudes in this population.

Although issues with the reliability of the measure mean that findings should be read with caution, the finding that higher levels of negative reactions to stigmatisation are associated with higher levels of psychological distress merits further consideration. If an individual feels angry or embarrassed by others' attitudes or chooses to withdraw socially this may have a negative impact on his or her well-being. Accordingly, interventions that help individuals to respond differently to negative attitudes may have a positive impact on their mental health. In addition, the observed trend, although not significant, toward women responding more negatively to the prejudice of others, suggests that this could be another area for future research to increase our understanding of how different genders perceive and respond to negative stereotypes.

The observed relationship between self-esteem and sense of power also indicates that interventions should look at how people with ID can feel more empowered to make decisions for themselves and have their views heard. It highlights the importance of having fora where individuals with ID are heard and ensuring that people with ID are empowered to make more decision for themselves which is not only important in its own right, but may have the added benefit of increasing self-esteem.

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Part 3: Critical Appraisal

Introduction

This aim of this study was to reach a better understanding of self-stigma in people with intellectual disabilities (ID). Self-stigma has been studied in a number of different fields including mental health, physical health, obesity and HIV/AIDS, but to-date has not been widely studied in the ID population. To further our understanding this study aimed to develop a new questionnaire to measure self-stigma and to assess how it relates to psychosocial factors, including psychological distress, and sociodemographic characteristics.

The findings from the study were that the measure we developed was not psychometrically sound. This critical appraisal will consider whether there were any changes to the methodology that could have resulted in a measure with improved psychometric properties, before thinking more broadly about using self-report questionnaires to measure feelings and attitudes in people with ID. I will consider how the measure was developed and whether the development process could have been improved, and will also consider the content of the measure. I will then consider the administration of the measure, and how this could have impacted on the reliability and validity of the questionnaire. I will also think about the ethical issues that were raised, how these were resolved and what lessons could be learnt for future research. Finally I will consider the feedback from the participants as well as plans for the dissemination of the results. I will finish with a personal reflection on the study.

Rationale for the study

People with ID face significant prejudice, as can be seen from high levels of bullying and hate crime, and evidence suggests that people with ID are aware of this prejudice (Jahoda, Wilson, Stalker & Cairney, 2010). However, people working in the field have a poor understanding of whether people with ID internalise negative stereotypes, which may lead to decreased well-being above and beyond that which is caused by the prejudices of others. There is also limited knowledge about what, if any, psychosocial factors or sociodemographic characteristics are associated with higher levels of self-stigma and stigma resistance.

One of the key reasons for the limited research in this area is the lack of a reliable measure that moves beyond asking people with ID if they are aware of the negative attitudes held by others, to assess whether they internalise these stereotypes and change their behaviour accordingly. The dearth of tools to measure self-stigma in people with ID was considered by Werner, Corrigan, Ditchman and Sokol (2012) in their review of measures, and they suggest that it could be down to assumptions that people with ID are not aware of negative attitudes held by others (Todd, 2000).

They draw the conclusion that a new measure should be based on the social cognitive model of self-stigma of Corrigan et al. (2002), which differentiates between awareness of, agreement with, and application of stereotypes. However, in discussing this, they do highlight the difficulties of developing a measure that is suitable for people with lower cognitive abilities. This concern was echoed in the early stages of this research when the proposal was presented to people working in the field. They warned that it could be too complex and abstract to ask people with

ID to differentiate between awareness of negative stereotypes about ID held by others, negative stereotypes about ID the person may hold themselves, and whether they applied such stereotypes to themselves. It is potentially this complexity, and the abstract nature of self-stigma, that has deterred researchers from attempting to measure self-stigma in people with ID the abstract nature of self-stigma was a significant challenge in creating this measure; one that we arguably did not succeed in meeting.

Issues with the development and design of the measure

As outlined in the empirical paper, the pilot version of the questionnaire went through many different iterations over a number of months. We considered adapting the Internalised Stigma in Mental Illness scale (ISMI; Ritsher, Otilingam & Grajales, 2003), which is widely used in mental health research, before deciding on adapting the Self-Stigma of Mental Illness Scale (SSMIS; Corrigan, Watson & Barr, 2006). We also considered different scales that could be used or adapted to assess self-esteem, psychological distress, reaction to stigma and sense of power. This initial stage of the development was completed by myself and my supervisor and the stereotypes that were included in the adapted version of the SSMIS were based on existing literature.

The first point at which people with ID were involved was when their input was sought on the face and content validity of the draft questionnaire. At this point we met with four self-advocates to get feedback on the draft measure, as well as other research materials including the information sheet and consent form. The self-advocates provided invaluable feedback, however, it was noticeable that the feedback focused on the presentation of the measure, such as the size and colour of the font, the inclusion of pictures and the response format. The self-advocates were encouraged to look at the questions in the self-stigma subscale but the feedback was limited. Their decision to focus their attention and feedback on presentational issues could have been because this was their priority but may also have been because they did not feel sufficiently confident to suggest that the content should be changed.

In thinking about their involvement using Hart's (1992) ladder of participation in research, our decision to involve self-advocates at this point in the process could be viewed as tokenistic as we were consulting them on a measure that had already been designed and therefore it was too late and not meaningful. Werner et al., (2012) suggest that to develop a new measure of self-stigma the first stage should be to employ qualitative research techniques such as focus groups or face-to-face interviews with people with ID, as well as their carers and families, to establish common stereotypes that exist for this population. An alternative approach used by Brooks, Davies and Twigg (2013), in developing the Clinical Outcome for Routine Evaluation for people with ID measure (CORE-LD), was to set up a research group including people with ID, who were an integral part of the research team and were heavily involved in designing the items in the measure.

The financial and time constraints of undertaking this project as part of the DClinPsy course, meant that it was not feasible to complete extensive qualitative research prior to designing the measure or to have a team of people with ID involved throughout, but it is arguable that the self-advocates could have been involved in a more meaningful fashion. For example, a one-day workshop with self-advocates could have been organised at the outset to get a better understanding of how people with ID view stigma and stereotypes. Increasing the involvement of self-advocates would have been important in its own right to ensure that people with ID are meaningful partners when carrying out research but could also have improved the comprehensibility of the measure that was piloted.

The piloting of the measure was perhaps the most difficult part of the research as it became apparent that there were significant issues with it, which had not been picked up in the earlier focus groups. The feedback that I received through this process helped to shape the measure but the problems with the pilot questionnaire meant that those participants who completed it at this stage in the research may have experienced unnecessary stress. One of the facilitators got in contact after the pilot measure had been completed with their group to say that they had felt very disappointed by the process. The facilitator felt that the measure had been too difficult to complete and had had a negative impact on the self-esteem of those who were being ask to take part. The feedback that she gave was very helpful in revising the questionnaire and administration procedures; in addition to the changes that were made to the measure, the decision was also made to send facilitators example items to ensure that it was appropriate for their groups.

Beyond the comprehensibility of the measure, another issue, that proved to be problematic in the design and development of it, was the amount and type of information it was trying to gather. In addition to trialling the new self-stigma items, the amended questionnaire was also aiming to measure self-esteem, negative reaction to stigmatisation, sense of power and psychological distress. This information was being collected to establish the validity of the new self-stigma measure and to investigate how the other psychosocial constructs related to self-stigma. In the initial version of the questionnaire, we used existing measures to assess the self-esteem, psychological distress and negative reaction to stigmatisation subscales - an adapted version of Rosenberg's Self Esteem scale (Sandhu & Dagnan, 1999), the CORE-LD (Brooks et al., 2013) and the reaction to stigma scale (Ali, Strydom, Hassiotis, Williams & King, 2008) respectively. They were included in the full version that had been validated for this population. Sense of power was assessed with an eight-item measure (Anderson, John & Keltner, 2012) that had been validated in the general population. It was adapted to make it more suitable for people with ID, but it had not been validated for this population. It rapidly became clear that there was a balance to be struck between using validated measure for each of the constructs in question or measuring them in a shorter from which was more suitable for this client group, but which had not been validated.

The first issue was raised by the Ethics Committee who questioned in relation to the CORE-LD whether it was ethical to ask participants about suicidal thoughts or self-harm outside of a clinic setting. It was considered important to include a measure of psychological distress and on balance it was preferable to have a scale that was in an unvalidated short-form than to have this subscale removed. It subsequently became clear, following work with the pilot group, that the number of items needed to be reduced significantly. The decision was taken to keep each of the subscales but to reduce the number of items that were measuring each of the psychosocial factors.

The decision to have a small number of items in each subscale is likely to have had a negative impact on the internal reliability and, possibly, on the test-retest reliability as set out in the empirical paper and on reflection it might have been preferable to reduce the number of constructs that the measure was hoping to assess. It could have been more user-friendly and more informative to have included more items from the perceived stigma scale (Ali et al., 2008)) and the CORE-LD (Brooks et al., 2013) and omitted items measuring self-esteem and sense of power. Self-esteem has been shown to be closely related to psychological distress in the mental health population as well as in people with ID and the measure might have been more manageable if we had focussed on the relationship between psychological distress and self-stigma, with the reasonable assumption that self-esteem would have varied in line with psychological distress. It was also perhaps over-ambitious to try and include the sense of power subscale in the measure. Sense of power is not a construct that has been explored in ID research, and therefore there was a very limited understanding of how it related to stigma and no validated measure.

Another option could have been to collect the data in more than one sitting. Limited time and resources, however, meant that it was not feasible for each of the groups to be visited twice, or four times if they were completing the measure twice, for the test-retest arm of the study. It would have also been an unnecessary burden on the groups, who were giving us their time voluntarily, and could have led to problems with missing data as participants might not have been able to attend the day centre or groups for both data collection sessions.

Although steps could have been taken to increase the reliability of the measure, it is also important to acknowledge that self-report pen and paper questionnaires may not be the most appropriate method to understand the inner lives of people with ID. In Hartley and MacLean's (2006) review of the reliability of response items when used with people with ID, which influenced some of our decisions in the design of the measure, the majority of the studies that were included were completed by people with borderline to mild ID, whereas the participants in this study also included people with moderate ID. Asking people with ID to complete questionnaires that are not suitable for their cognitive abilities will not only result in unreliable data but could potentially have a deleterious effect as evidenced in the feedback from the pilot group. It is therefore important that researchers are very clear about which part of the ID population the measure has been designed for.

There is also a question about the suitability of using questionnaires to measure abstract feelings or attitudes as opposed to overt behaviours in people with ID. It is perhaps more appropriate to use questionnaires for measuring overt behaviour as this could be easier to recall and is likely to be more stable than attitudes (Cuskelly, Moni, Lloyd & Jobling, 2013). In contrast the poor reliability of the results observed in this study may suggest that people with ID may have more unstable attitudes and cannot therefore be reliably assessed in self-report measures. The answer to addressing these issues is not to shy away from carrying out research with people with ID, but to involve them more in the design and to think carefully about the most suitable means of assessment rather than merely adapting methods that have proven to be reliable in the general population.

Administration of measure

The measure was completed in a group setting. This was in part due to limited time and resources, but also, because the intention was to use the questionnaire to measure the effectiveness of a group programme designed to help people with ID to resist stigma (STORM), it was important to assess the feasibility of completing it in a group setting. The decision to use this form of administration raised issues with reliability and potentially ethical issues, discussed further below. Although the researchers did everything to avoid these problems, it is important to think about whether this way of collecting data is suitable for research with people with ID, and what additional measures could be put in place in future if researchers use similar methods.

Reliability

Questions about the reliability of the measures are discussed in more detail in the empirical paper, but in this part I will consider the practical difficulties of completing the measure in a group and whether these could have been avoided if data had been collected individually. The first difficulty was the variation in the composition of the group both in terms of the number of participants and the intellectual functioning of the individuals making up the group. This was more problematic when collecting the data from the groups who were only completing the measure, as in general those completing the STORM programme were more closely vetted to ensure that they were suitable to take part. As a consequence the latter groups were mostly smaller and the participants tended to have a similar levels of intellectual functioning.

The varying cognitive abilities of the group was made more problematic when the groups were larger as there was less opportunity for the researchers to gauge the participants' understanding of the questions. Where it was clear that a participant was either not able to give consent or did not understand the questions, his or her data were not included in the analysis. However, because the questionnaires were not completed individually, the extent to which the participants had a good understanding of each questions was not always clear. One solution that could have addressed this problem would have been to include pre-test questions that required a “never” response such as “I like rotten food” and or a “sometimes” or “always” response such as “I like money”. The inclusion of such questions has been shown to ensure that respondents are reliably able to reply to questions (Hartley & MacLean, 2006).

Another consequence of the different abilities in the larger groups was that participants with higher intellectual functioning were observed to be filling in the answers for people who were struggling, and on occasions facilitators were also observed answering on behalf of the client. When the measure was introduced the researchers specifically asked participants and facilitators not to discuss the answers and where this was observed to have occurred the respective responses were marked as invalid. However, there were concerns that in the bigger groups it was not always possible to have oversight of whether this was happening. This points to the importance of completing the measure individually or in small groups where there is good oversight.

Ethical issues

The use of group administration also raised ethical issues, the first of which related to participants’ ability to decide whether to take part in the research and complete the questionnaire. Again this was particularly problematic for the groups that only completed the measure rather than it being part of the STORM programme. For this arm of the research, the measure was completed as part of the normal group activities and although it was made clear to those attending each group that participation was voluntary, for those who chose not to take part in the research there were often no alternative activities, making non-participation an unattractive option. There were a number of incidents where it was felt by researchers that group facilitators were putting pressure on people to take part in the research. On such occasions, researchers reminded the staff that participation needed to be voluntary, but some participants may have felt implicit pressure to take part.

There were also ethical difficulties around confidentiality as people wanted to share or to discuss their answers with the group. On a number of occasions researchers had to stop conversations that could have been important for the participants. This felt difficult and could have been viewed as disempowering for the participants as they may have felt that they were not being listened to. The researchers always offered a space to have discussions after all the measures had been completed, however, participants rarely used this time to return to issues that had been raised previously. If the measure had been completed on a one-to-one basis there could have been opportunities to discuss the issues that were triggered by the measure without raising concerns about confidentiality; this could have been helpful for participants and also provided researchers with additional useful qualitative information.

The constructs that were being measured were emotive and the decision to administer the questionnaire in a group rather than individually could have added to any difficult emotions felt by the participants. Steps were taken to reduce the possibility of this; items were removed that related to self-harm and suicide in line with comments from the Ethics Committee and participants were also warned at the outset, in the information sheet, about the potentially upsetting nature of the questions. Facilitators and researchers were also available to speak to the participants after the measures were completed. However, the size of the group and the request not to talk during the administration may have deterred participants from subsequently speaking freely about any difficult emotions that they experienced whilst completing the measure.

Finally, the practical challenges with the administration meant that around a quarter of the completed measures had to be disregarded as they were not considered to be reliable either because there were concerns about whether the participants understood the questions or because others had assisted them in completing the questionnaire. Included in the data which were disregarded was data from one entire group. This raises ethical issues about asking people to spend time completing the measure but not ensuring that there was sufficient support to enable the participants to complete it in such a way that the data could reliably be used. Whilst every effort was made to avoid this happening it does raise questions about the suitability of this form of administration.

Feedback from the participants

There was feedback from the participants and the group facilitators about comprehensibility, and some participants said that they were unwilling to complete items and subscales because they did not understand them. These are discussed in more detail in the empirical paper, but the difficulties were predominantly around the use of double negatives, and the difficulty in differentiating between the stereotypes that participants held towards others with ID and the extent to which they applied these to themselves.

Participants also spoke about the problematic emotions that some of the items raised for them. Participants did not find it easy to think about their own psychological distress and some of the issues raised in the self-stigma subscale also felt emotive for participants. However, while people talked about the challenges of answering the questions, they also said that they felt that it was important to think about these issues and in that respect they had found it helpful to complete the measure.

Finally, there was also feedback from the group facilitators and the participants that they had enjoyed taking part in the research. They appreciated the fact that we were seeking information from people with ID rather than making assumptions as to how they feel about the prejudices of others, and considered that it was helpful to include the voices of people with ID in academic research. A number of the groups made a request that we visit them again to report on the findings of the research, as members can find it frustrating when they did not see the fruits of their work. Although it is has not been possible to attend each of the groups to update them on the research, an event has been organised for participants and group facilitators where the results will be presented and participants can share their own experiences.

Reflections on the study

Although there were problems with the development and administration of the measure, which meant that caution needs to be taken with the results, it produced some useful initial data about the relationship between the different psychosocial factors and some important learning points about how to develop measures for people with ID. On a personal level I also enjoyed carrying out this research and gained invaluable insights into the lives of people with ID and how stigma impacts them. I also became aware of how much the people participating in the study had to share about their experiences, and that this was not always picked up through using quantitative measures.

Essential work is being done by Mencap and other organisations to combat the prejudice towards people with ID in the general population, but it is equally important that people with ID are given the confidence and strategies to stand-up to prejudice where it continues to exist. To improve our understanding, as well as to measure the effectiveness of new interventions it is necessary to have a psychometrically-sound measure of self-stigma. I hope that researchers working in the field will continue to look at self-stigma in people with ID and will develop new ways of measuring self-stigma that are not only reliable but also help others to understand the experiences of those that experience negative attitudes from others and how it impacts their lives.

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Appendix 1 – Manual for Quality Scoring Quantitative Studies

(Kmet, Cook & Lee, 2004)

1. Question or objective sufficiently described?

Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is not considered sufficiently described.

Partial: Vaguely/incompletely reported (e.g. “describe the effect of ” or “examine the role of ” or “assess opinion on many issues” or “explore the general attitudes”...); or some information has to be gathered from parts of the paper other than the introduction/background/objective section.

No: Question or objective is not reported, or is incomprehensible.

2. Design evident and appropriate to answer study question?.

Yes: Design is easily identified and is appropriate to address the study question / objective.

Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question.

No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified.

3. Method of subject selection is described and appropriate.

Yes: Described and appropriate. Selection strategy designed (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies

or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., “cancer” -- ICD code or equivalent should be provided). Studies of volunteers: methods and setting of recruitment reported. Surveys: sampling frame/ strategy clearly described and appropriate.

Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as “volunteers” or “healthy volunteers”. Surveys: target population mentioned but sampling strategy unclear.

No: No information provided. Or obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). Or presence of selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study).

4. Subject characteristics sufficiently described?

Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). Decision analyses: baseline estimates for input variables are clearly specified.

Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). Or incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). Decision analyses: incomplete reporting of baseline estimates for input variables.

No: No baseline / demographic information provided.
Decision analyses: baseline estimates of input variables not given.

5. Outcome measures well defined and robust to measurement / misclassification bias? Means of assessment reported?

Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, “objective” criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. Surveys: clear description (or reference to clear description) of questionnaire/interview content and response options. Decision analyses: sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, or not sure (i.e., not reported in detail, but probably acceptable). Or precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. Or instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). Surveys: description of questionnaire/interview content incomplete; response options unclear. Decision analyses: sources of uncertainty are defined only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. Or measures employ only ill-defined, subjective assessments, e.g. “anxiety” or “pain.” Or obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). Surveys: no description of questionnaire/interview content or response options. Decision analyses: sources of uncertainty are not defined for input variables.

6. Analysis described and appropriate?

Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”/“Kaplan-Meier with log rank tests”, etc.) and appropriate.

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. Or minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). Or multiple testing problems not addressed.

No: Analysis methods not described and cannot be determined. Or obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). Or a study with a descriptive goal / objective is over-analyzed.

7. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)?

Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model.

Partial: Undefined “+/-“ expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model.

No: No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis.

8. Controlled for confounding?

Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at the design or an alysis stage (e.g., matching, subgroup analysis, multivariate models, etc). Decision analyses: dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. Or control of confounding reportedly done but not completely described. Or randomized study without report of comparability of baseline characteristics. Or confounding not considered, but not likely to have seriously distorted the results. Decision analyses: incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. Decision analyses: dependencies between variables not considered.

9. Results reported in sufficient detail?

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. Or difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or “n” changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of “unknown” is not used where needed). Or results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as “more likely” without quantitative report of actual numbers).

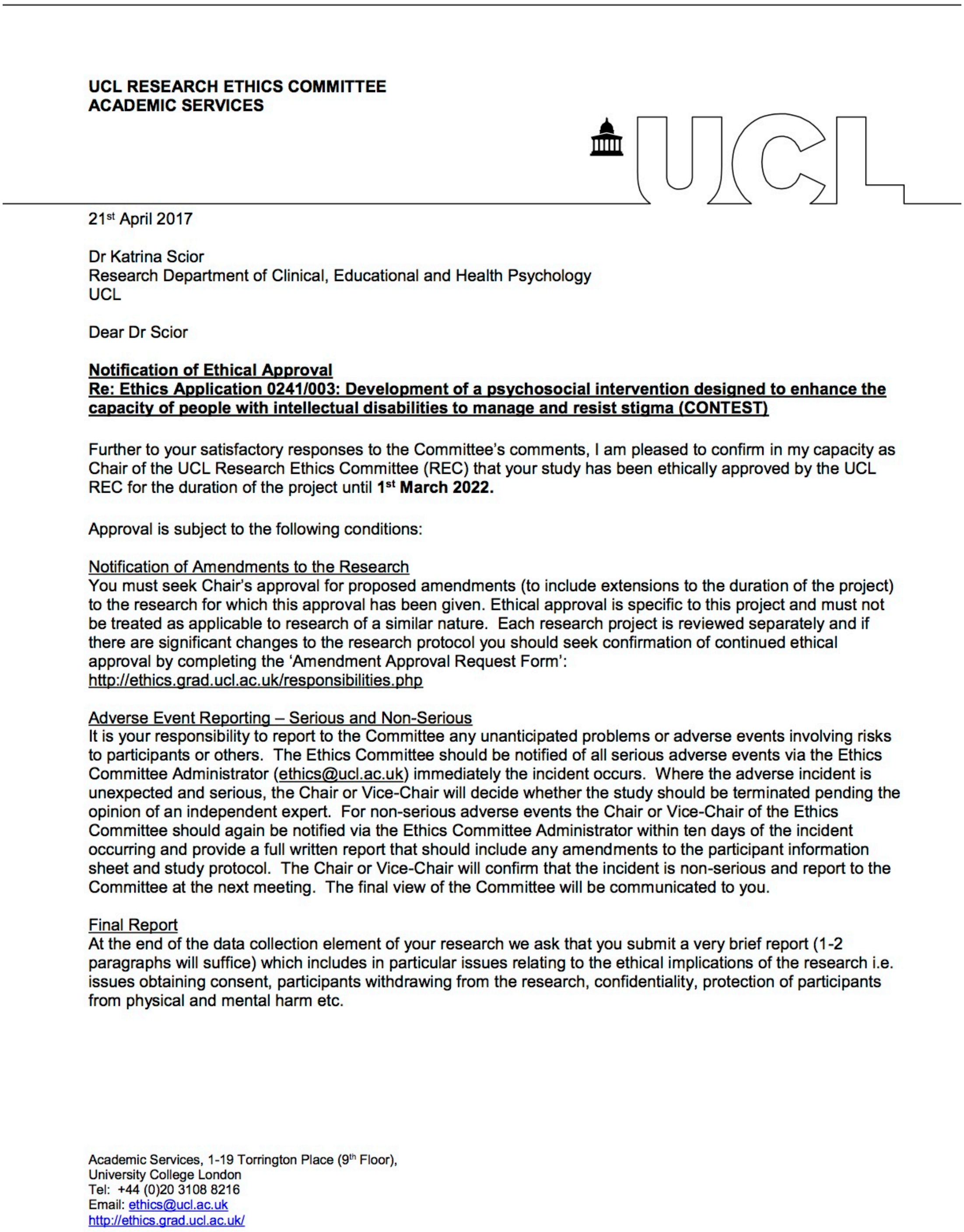
10. Do the results support the conclusions?

Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren’t based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in addition to rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., “suggesting,” “possibly”).

Partial: Some of the major conclusions are supported by the data, some are not. Or speculative interpretations are not indicated as such. Or low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

No: None or a very small minority of the major conclusions are supported by the data. Or negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. Or conclusions are missing. Or extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/ strategy).

Appendix 2 – UCL Research Ethics Committee approval



UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES

21st April 2017

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

Dear Dr Scior

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

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

Approval is subject to the following conditions:

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

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

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

Academic Services, 1-19 Torrington Place (9th Floor),
University College London
Tel: +44 (0)20 3108 8216
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

With best wishes for the research.

Yours sincerely

[redacted]

Dr Lynn Ang
Interim Chair, UCL Research Ethics Committee

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

Appendix 3 – Information Sheet for Group Facilitators

Myself and the World Questionnaire- Study Information

Background

- Research shows that people with learning disabilities face negative consequences because of the stigma associated with having a learning disability. Stigma refers to negative views about a person or group due to a characteristic that makes them different from other members of society.
- Despite positive changes in policies, service provision and societal views, negative attitudes and discrimination remain everyday realities for many people with learning disabilities.
- Despite a clear need to do more to empower people with learning disabilities to manage and resist stigma, to date few interventions have targeted this and none have been shown to be effective.
- Developing effective ways of promoting resilience to stigma and addressing vulnerability to self-stigmatisation among people with learning disabilities is likely to have positive effects on their mental health, well-being and social interactions.

Who are we?

- We are a team of researchers from University College London (UCL). The team includes researchers, clinicians and self-advocates with learning disabilities from different parts of the UK.
- Our research aims to advance our understanding of learning disability stigma.

What is this study about?

- We want to find out more about how people with learning disabilities feel about the way they are treated in society and the way they feel about themselves as a result.
- We feel that hearing directly from people with learning disabilities about their experience is important and we have developed a new questionnaire (**Myself and the World**) to measure this.
- We are inviting groups of people with learning disabilities to complete this questionnaire to help us to assess whether it can successfully measure how people feel about themselves and the way they are treated in society.

The 'Myself and the World' questionnaire:

- Draws on existing questionnaires as well as new questions the research team have added
- Consists of 30 questions and takes between 30 and 45 minutes to complete
- Contains questions that ask about how individuals feel about themselves, including how empowered they feel and how they feel having a learning disability affects them
- Is designed to be completed by individuals in a group setting, with support

All groups who take part in the trial of the measure will be entered into a prize draw to win £100 towards their group/activity fund as a token of appreciation.

Who can take part?

- We are looking for groups of people with learning disabilities to complete the Myself and the World questionnaire (regardless of whether an educational, social, activity-based or self-advocacy setting)
- As part of this, it is important that the group members:
    - Have a mild-moderate learning disability
    - Are aged 16 or over
    - Ideally have someone that they can talk to for support

What will I need to do as a group facilitator?

- We are asking you to assist us in co-ordinating a group to complete the questionnaire. This would involve:
    - Identifying a group to take part and providing them with information about the study
    - Assisting the researcher to seek informed consent from group members
    - Allowing the researcher to work with the group to complete the questionnaire and a short demographic form (6 questions) as well
    - Supporting the researcher where needed in facilitating individuals to complete the questionnaire.
- We would require 1.5 hours to complete the above activities.

Contact details: Should you have any queries or require any further information, please do not hesitate to contact Katrina Scior (Project Lead):
Tel- 02076 791 845
Email- k.scior@ucl.ac.uk

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

Appendix 4 – Information Sheet for Carers and Families

Myself and the World Questionnaire – Study Information

Dear Family/Supporter of ________________________,

As a family member or someone who supports __________________ we are writing to let you know that they have agreed to complete a questionnaire called 'Myself and the World'. A member of the University College London (UCL) research team will attend ________________________________ *(name of group)* on ___________________________ *(day)* at ____________________________ *(time and place)* to support group members to complete the questionnaire.

We have enclosed more information about the research study with this letter.

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

Kind Regards,
Katrina Scior, Lisa Richardson and Sophini Logeswaran

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

Tel- 02076 791 845
E-mail- k.scior@ucl.ac.uk

Myself and the World Questionnaire – Study Information

Background- why we are developing a new questionnaire and the research:

- People with learning disabilities face negative feelings and experiences because of the way they can be viewed by others. Despite positive changes in policies, services and societal views, negative attitudes and discrimination remain everyday realities for many people with learning disabilities.
- There is a clear need to do more to understand how people with learning disabilities are affected by such feelings and experiences, but there is currently no measure to help clinicians and researchers understand the impact.

Who are we?

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

What is this study about?

- We want to find out more about how people with learning disabilities feel about the way they are treated in society and the way they feel about themselves as a result.
- We feel that hearing directly from people with learning disabilities about their experience is important and we have developed a new questionnaire (Myself and the World) to measure this.
- We are inviting groups of people with learning disabilities to complete this questionnaire to help us to assess whether it can successfully measure how people feel about themselves and the way they are treated in society.

The 'Myself and the World' questionnaire:

- Draws on existing questionnaires as well as new questions the research team have added
- Consists of 30 questions and takes between 30 and 45 minutes to complete
- Contains questions that ask about how individuals feel about themselves, including how empowered they feel and how they feel having a learning disability affects them Is designed to be completed by individuals in a group setting, with support

What would involvement look like for group members?

- The group facilitator will introduce the questionnaire to group members and see who is interested in completing it, as part of a regular group session.
- A researcher will meet with the interested group members, go through an information sheet and complete consent forms.
- The interested group members will be asked to fill in the questionnaire in the group session with the help of UCL researchers and the group facilitator.

Providing support to group members

- It is possible that completing the questionnaire could bring up sad or difficult feelings in participants, as they may be reminded about the way others can view people with learning disabilities.
- We will try our best to support group members who feel this way.
- It is possible that group members may wish to speak to their carers or friends about their feelings, thoughts and experiences related to the topics asked about in the questionnaire, which is why we are giving you this information sheet.

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

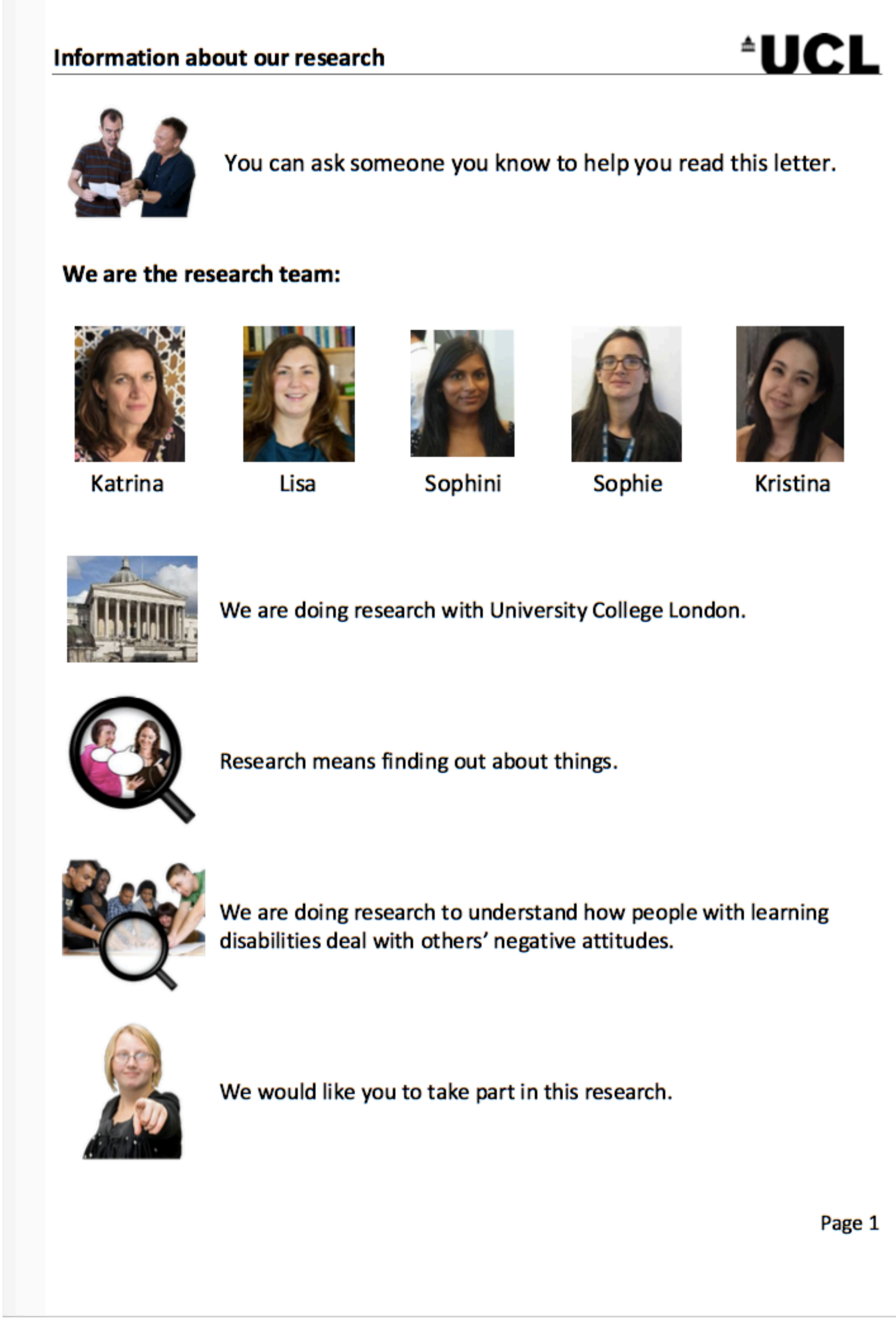
Mencap – FamilyHub: An online community for parents and family carers to connect with others, to share triumphs and challenges, and a place for support and tips
https://www.mencap.org.uk/familyhub

National Family Carer Network: a charity that aims to promote the voice and rights of family carers supporting a person with a learning disability
http://www.familycarers.org.uk/
info@familycarers.org.uk

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

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

Appendix 5 – EasyRead Information Sheet



Information about our research UCL

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

We are the research team:

Katrina Lisa Sophini Sophie Kristina

We are doing research with University College London.

Research means finding out about things.

We are doing research to understand how people with learning disabilities deal with others' negative attitudes.

We would like you to take part in this research.

Page 1

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

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

Why we are doing this research

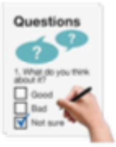
We want to learn more about how people with learning disabilities deal with other people's attitudes to their disability.

We also want to understand why some people feel bad about having a learning disability.

We are asking you to take part

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

About the research

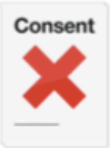


We will ask you to answer some questions about you and how you feel.

Choosing to take part in research

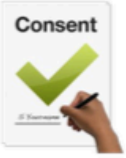
You can choose if you want to take part in the research.

It's up to you.



You can say no.

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



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

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

Changing your decision

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

You don't have to tell us why.

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

What we do with your answers

Your answers will be confidential.

That means we don't share it with anyone.

Only the research team will see your answers.

Where we keep your answers

We will keep your answers in a locked place.

Your name will not be on the answers.

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

We will not use your name in our report.

Good things about taking part

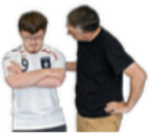
Your answers will help us understand how people with learning disabilities deal with others' attitudes.

Your answers will help us understand why some people feel sad or angry because of their learning disability.

What we find out might help to support people with learning disabilities who feel sad or angry because of their disability.

Things that might be difficult

Some questions might be difficult or make you feel sad.



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

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

How to make a complaint

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

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

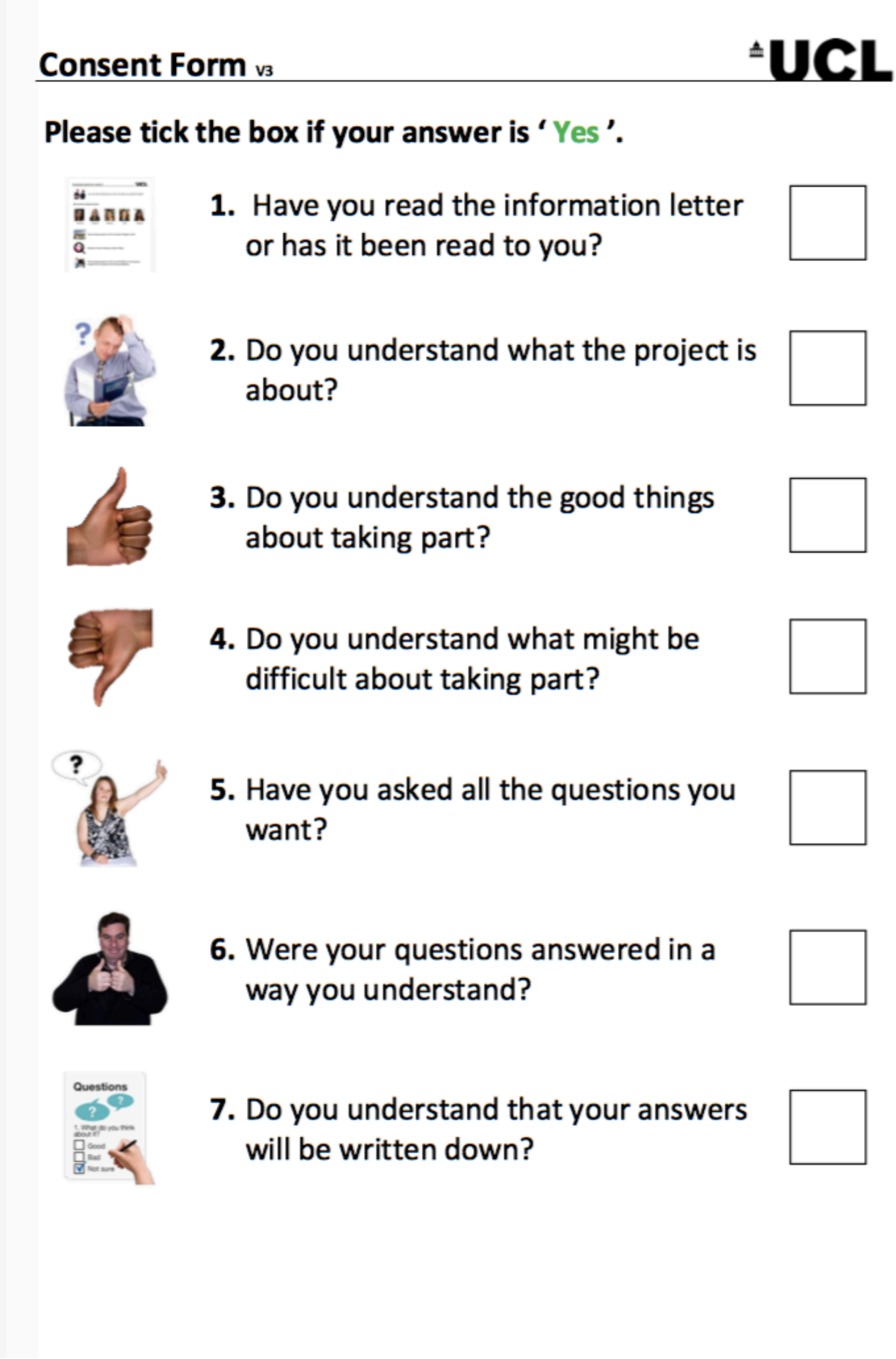
You can contact Katrina Scior:

E-mail: k.scior@ucl.ac.uk
Phone: 0207 679 1845

We will do our best to sort out the problem.

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

Appendix 6 – Consent Form



Consent Form V3

UCL

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

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

2. Do you understand what the project is about? ☐

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

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

5. Have you asked all the questions you want? ☐

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

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

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

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

10. Are you happy to take part? ☐

✓ **If you want to take part, please sign below:**

Name: ____________________________________

Signature: _________________________________

Date: _____________________________________

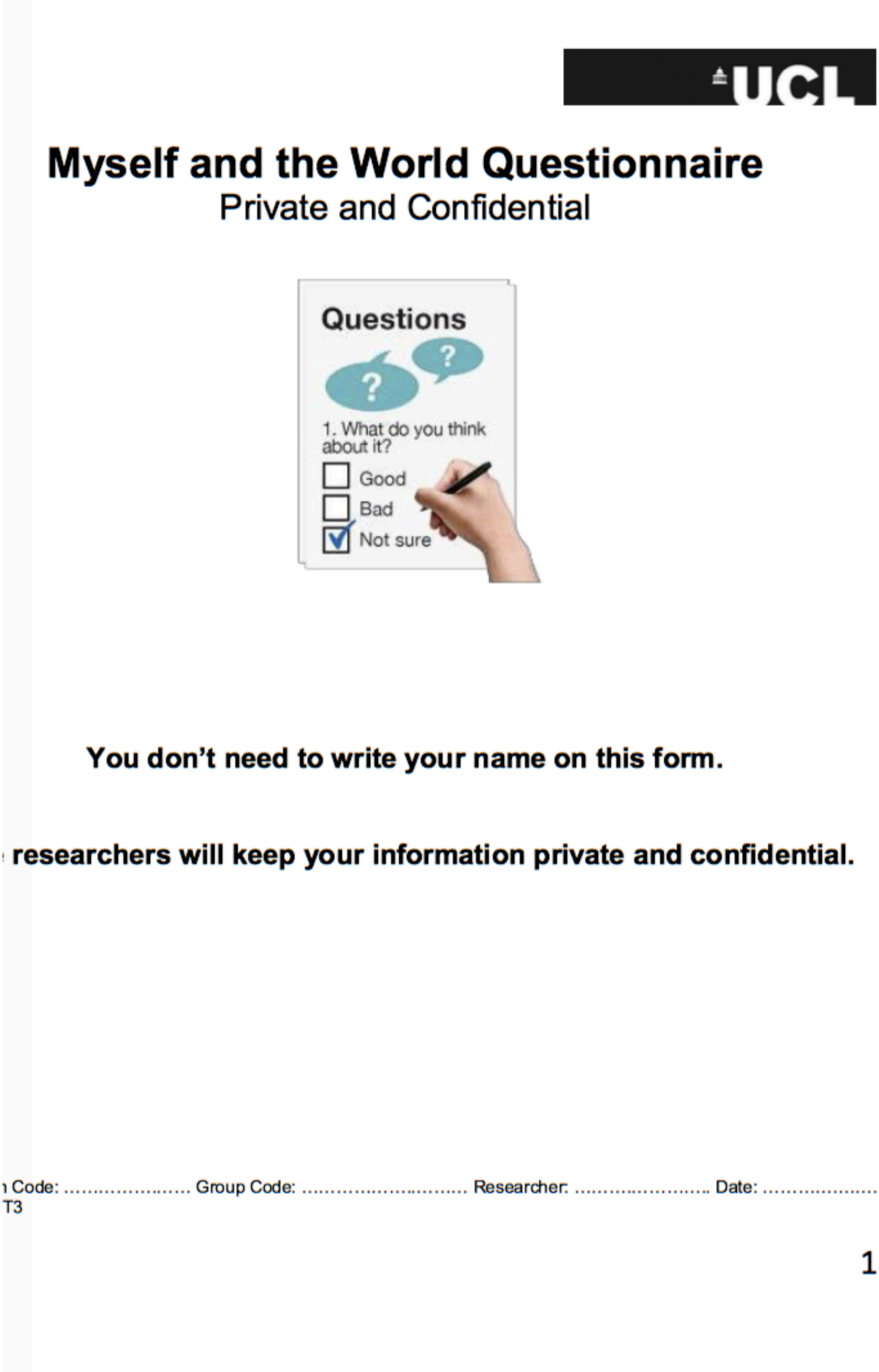
✗ **If you don't want to take part, you don't have to sign.**

The researcher will complete this section:

Researcher's Name: ____

Signature: ____________________________ Date: ____________________________

Appendix 7 – Myself and the World Questionnaire



UCL

Myself and the World Questionnaire

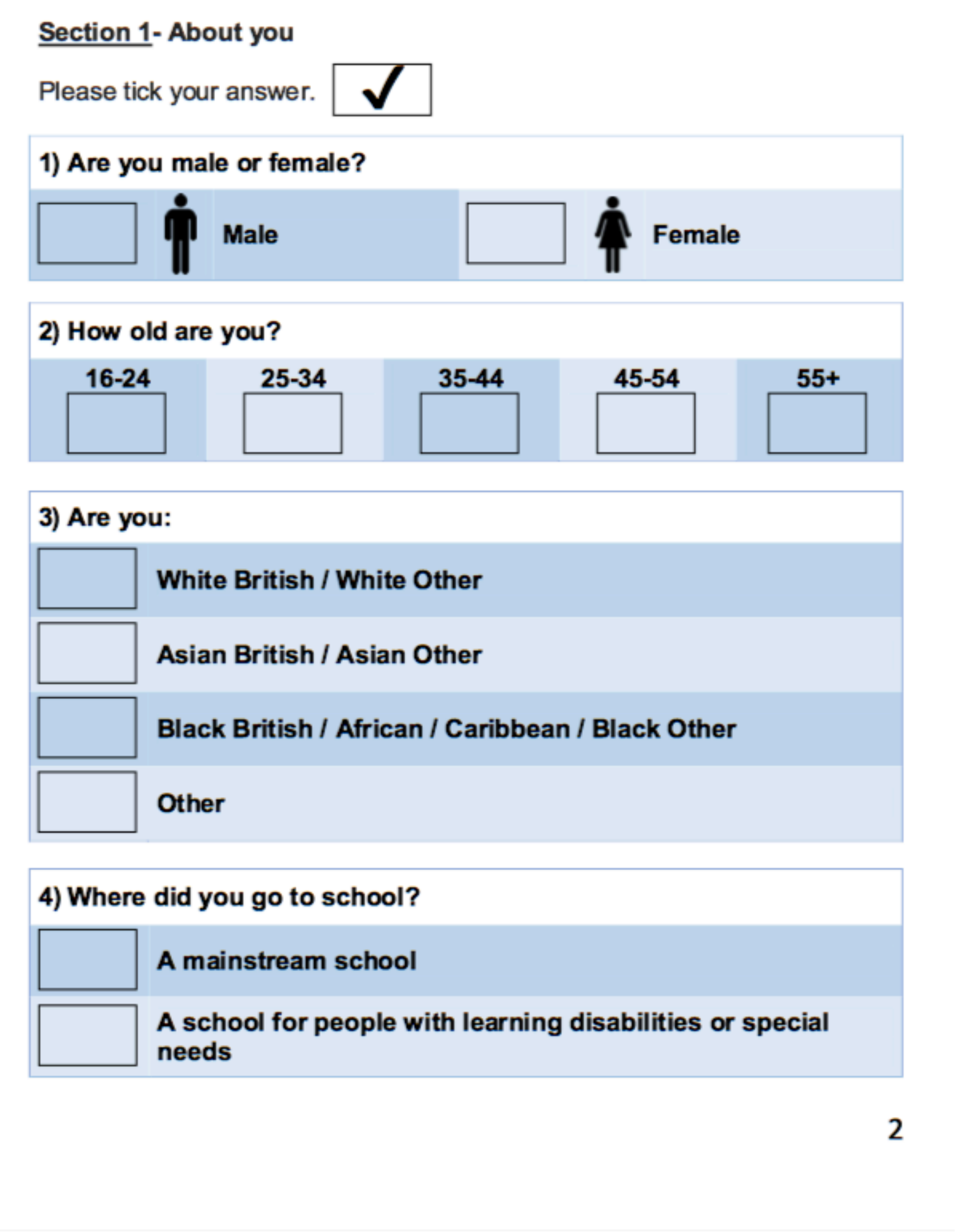
Private and Confidential

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

researchers will keep your information private and confidential.

Code: …………………. Group Code: ………………………. Researcher: …………………….. Date: ………………..
T3

1



Section 1- About you

Please tick your answer. ☑

1) Are you male or female?

☐ **Male** ☐ **Female**

2) How old are you?

16-24	25-34	35-44	45-54	55+
☐	☐	☐	☐	☐

3) Are you:

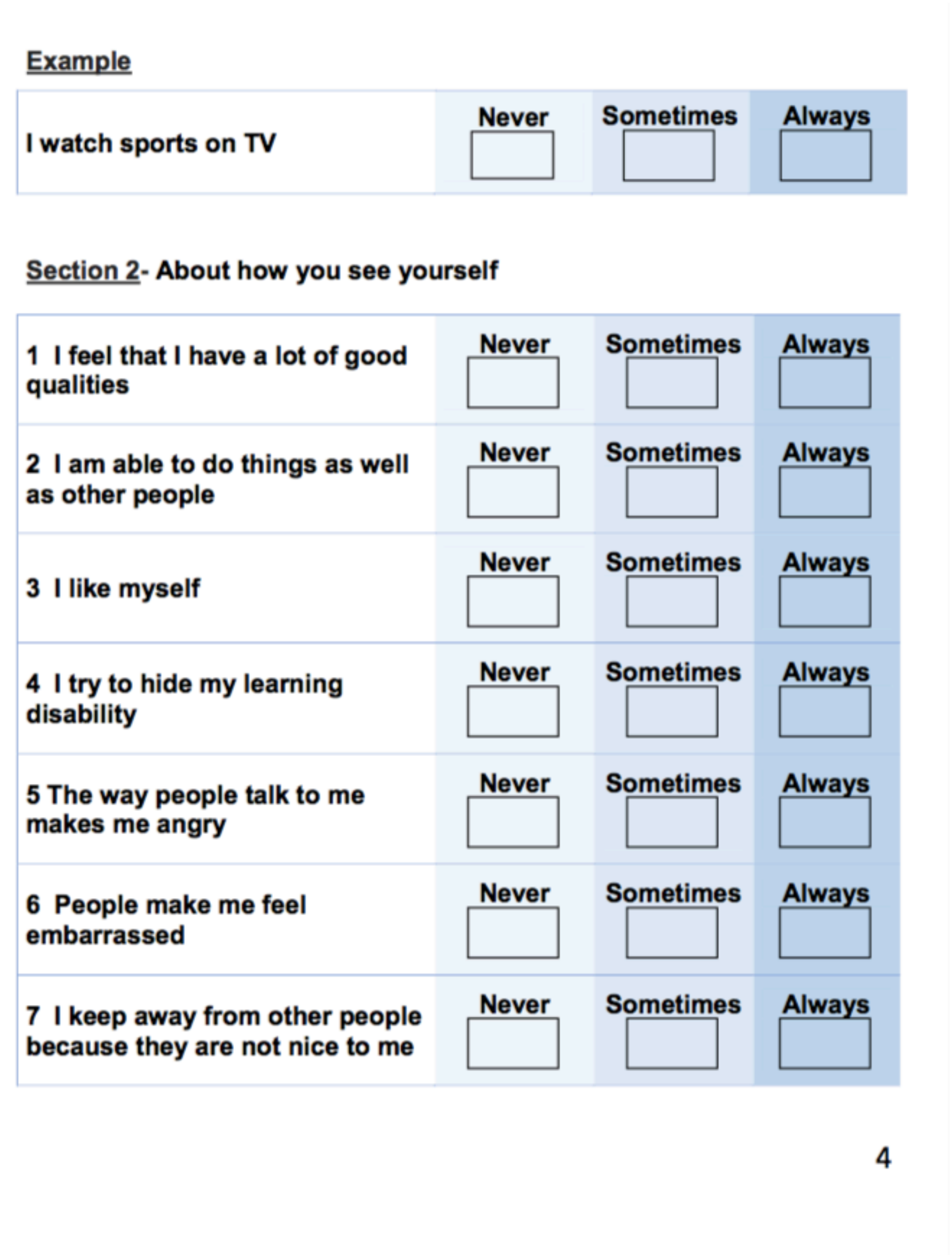
- ☐ **White British / White Other**
- ☐ **Asian British / Asian Other**
- ☐ **Black British / African / Caribbean / Black Other**
- ☐ **Other**

4) Where did you go to school?

- ☐ **A mainstream school**
- ☐ **A school for people with learning disabilities or special needs**

5) Who do you live with?	
☐	On my own
☐	With your parent(s), or another family member
☐	With your partner, husband or wife
☐	In supported living
☐	Other

6) Do you have a disability?			
A learning disability	Yes ☐	No ☐	Don't know ☐
A physical disability	Yes ☐	No ☐	Don't know ☐
A sight or hearing disability	Yes ☐	No ☐	Don't know ☐
Autism	Yes ☐	No ☐	Don't know ☐

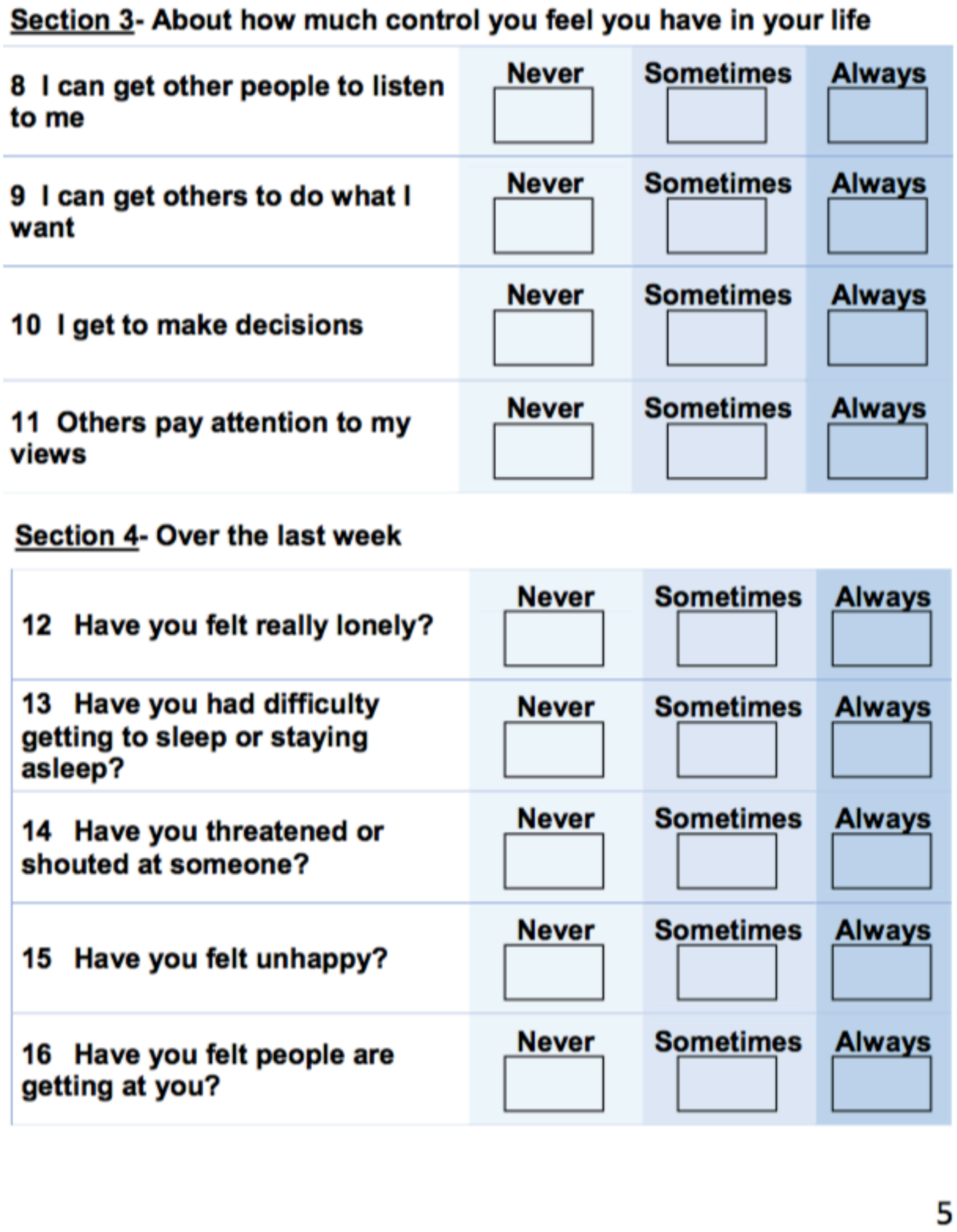


Example

I watch sports on TV	Never ☐	Sometimes ☐	Always ☐

Section 2- About how you see yourself

1 I feel that I have a lot of good qualities	Never ☐	Sometimes ☐	Always ☐
2 I am able to do things as well as other people	Never ☐	Sometimes ☐	Always ☐
3 I like myself	Never ☐	Sometimes ☐	Always ☐
4 I try to hide my learning disability	Never ☐	Sometimes ☐	Always ☐
5 The way people talk to me makes me angry	Never ☐	Sometimes ☐	Always ☐
6 People make me feel embarrassed	Never ☐	Sometimes ☐	Always ☐
7 I keep away from other people because they are not nice to me	Never ☐	Sometimes ☐	Always ☐

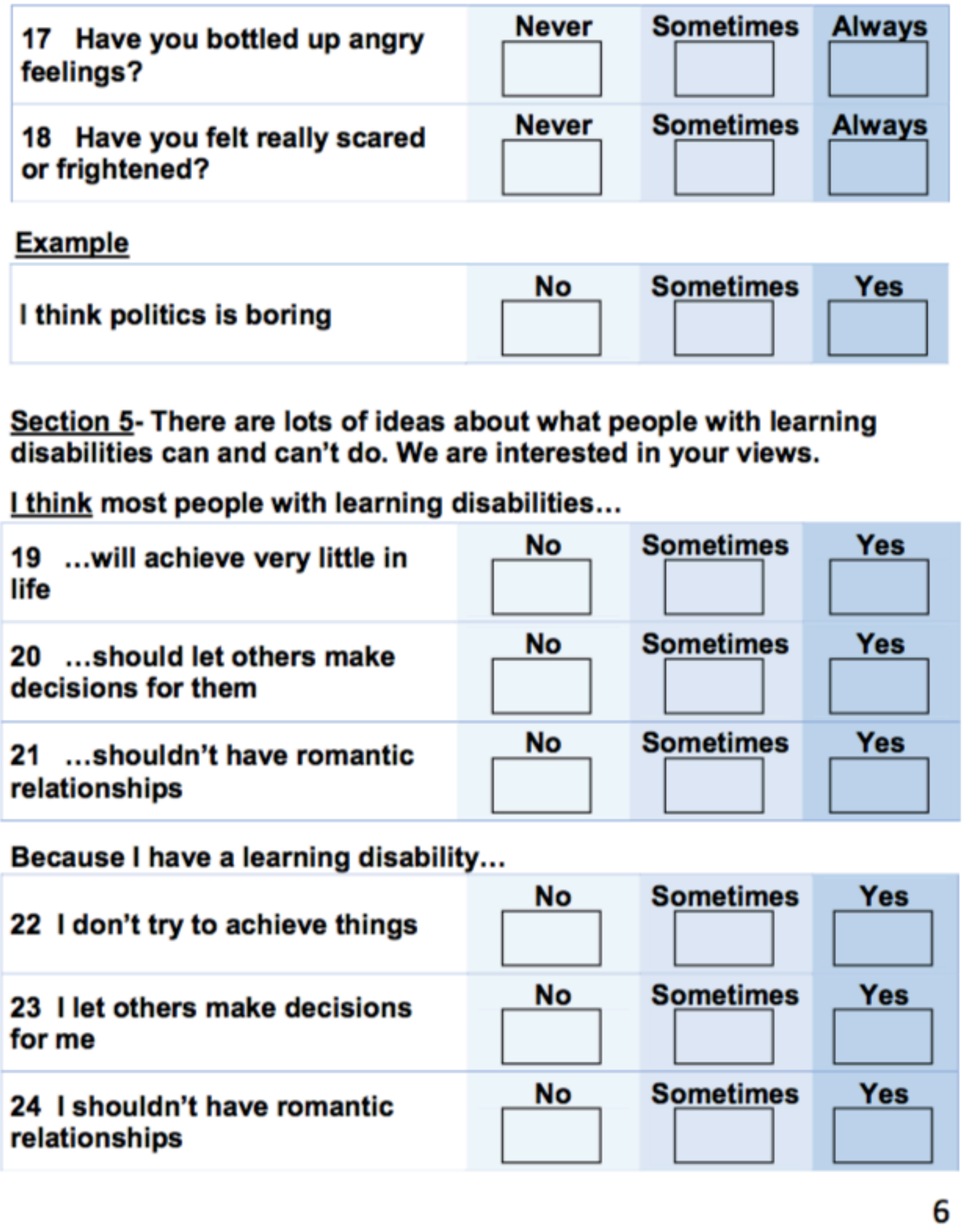


Section 3- About how much control you feel you have in your life

8 I can get other people to listen to me	Never ☐	Sometimes ☐	Always ☐
9 I can get others to do what I want	Never ☐	Sometimes ☐	Always ☐
10 I get to make decisions	Never ☐	Sometimes ☐	Always ☐
11 Others pay attention to my views	Never ☐	Sometimes ☐	Always ☐

Section 4- Over the last week

12 Have you felt really lonely?	Never ☐	Sometimes ☐	Always ☐
13 Have you had difficulty getting to sleep or staying asleep?	Never ☐	Sometimes ☐	Always ☐
14 Have you threatened or shouted at someone?	Never ☐	Sometimes ☐	Always ☐
15 Have you felt unhappy?	Never ☐	Sometimes ☐	Always ☐
16 Have you felt people are getting at you?	Never ☐	Sometimes ☐	Always ☐



17 Have you bottled up angry feelings?	Never ☐	Sometimes ☐	Always ☐
18 Have you felt really scared or frightened?	Never ☐	Sometimes ☐	Always ☐

Example

I think politics is boring	No ☐	Sometimes ☐	Yes ☐

Section 5- There are lots of ideas about what people with learning disabilities can and can't do. We are interested in your views.

I think most people with learning disabilities…

19 …will achieve very little in life	No ☐	Sometimes ☐	Yes ☐
20 …should let others make decisions for them	No ☐	Sometimes ☐	Yes ☐
21 …shouldn't have romantic relationships	No ☐	Sometimes ☐	Yes ☐

Because I have a learning disability…

22 I don't try to achieve things	No ☐	Sometimes ☐	Yes ☐
23 I let others make decisions for me	No ☐	Sometimes ☐	Yes ☐
24 I shouldn't have romantic relationships	No ☐	Sometimes ☐	Yes ☐

Appendix 8 – Response Formats used in Other Measures for People with ID

Measure	**No. of items**	**Available responses**
Clinical Outcomes for Routine Evaluation-LD (Brooks, Davies & Twigg, 2013)	3	Not at all, sometimes, a lot
Hospital Anxiety & Depression Scale-LD (Chadwick, Trower & Dagnan, D., 2000)	4	All of the time, often, sometimes, never
Glasgow Anxiety Scale-ID (Mindham & Gillespie, 2003)	3	No, sometimes, always
Glasgow Depression Scale-ID (Cuthill, Gillespie & Cooper, 2003)	3	No, sometimes, always
Psychological Therapies Outcome Scale-ID (Vlissides, Beail, Jackson, Williams & Golding, 2017)	4	Not at all, a little bit, sometimes, a lot
Maslow Assessment of Needs Scale-LD (Skirrow & Perry, 2009)	5	Nearly always, most of the time, about medium, not very often, hardly ever
Perceived Stigma – ID (Ali, Strydom, Hassiotis, Williams & King, 2008)	2	Yes/ no
Impact of Events Scale – ID (Hall, Jobson & Langdon, 2014)	3	A little bit, in the middle, a lot
Personal Wellbeing Index -ID (Cummins &Lau, 2005)	10 point Visual Analogue Scale	n/a
The Social Comparison Scale (Dagnan & Sandhu, 1999)	bipolar options on 12.5cm Visual Analogue Scale	n/a
Stigma Scale (young adults) (Szivos-Bach, 1991)	5	Never, sometimes, half the time, often, nearly & always
The Evaluative belief scale (Chadwick, Trower & Dagnan, 1999)	5	Never true, hardly ever true, sometimes true, often true, always true

Appendix 9 – Joint Project

This study was part of the larger CONTEST project, that is developing and testing the feasibility and preliminary outcomes of psychosocial group intervention for people with intellectual disabilities to help them to manage and resist stigma (STORM). The Chief Investigator on the project was Dr Katrina Scior, and in addition to Krisitna Fenn (another D.Clin.Psy trainee), there was also a Research Assistant working full-time (Sophini Logeswaran/ Laurie Poole) and a Research Associate working part-time (Lisa Richardson). We also received advice from a Steering Group made up of clinicians and academics working in the field and self-advocates with intellectual disabilities.

The early preparatory work with done jointly between myself and Kristina Fenn. This included applying for ethical approval, as well as creating the information sheets and consent forms. I designed the measure with input from Katrina Scior and the Research Assistant.

The team, myself, Kristina, the Research Assistant and the Research Associate, all contributed to the recruitment for both the STORM programme and the participants who only completed the measure. We also all shared out the data collection. I attended groups who were trialling the STORM programme as well as collecting data from groups who were only completing the measure. We also shared out the data entry.