What predicts self-esteem of individuals 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.

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Overview

This thesis is presented in three parts, with an overall focus of self-esteem of people with intellectual disabilities. In this thesis, the term "intellectual disability" is used synonymously with "learning difficulty/disability". While it reflects the desire for consistency and clarity in the international literature in order to build knowledge and understanding, it is not without problems. Disability is defined by society and is motivated by social, economic, and political contexts and is loaded with stigma. The term "learning difficulty" may be preferred among self-advocates in the UK. However, this is a term that could have an entirely different meaning among mainstream educators, who might understand it as a specific learning difficulty such as dyslexia. In view of the differences in terms depending on social context, the decision was made to use "intellectual disability" in hope to help researchers grow the body of literature available, in order to serve this population in the long run.

The first part comprises a systematic literature review of the levels of self-esteem in persons with intellectual disabilities and links with mental health outcomes. Reviewed studies provided mixed evidence on the levels of self-esteem, suggested that factors such as engagement in life were related to higher self-esteem, and demonstrated the co-occurrence of low self-esteem and depression. Implications of the review include the need for more research using longitudinal designs to answer questions about trajectory.

The second part comprises a quantitative cross-sectional study on the predictors of self-esteem of people with intellectual disabilities. The findings indicated that there was no association between the sociodemographic characteristics surveyed and self-esteem. Higher self-esteem was associated with higher levels of wellbeing, sense of social power, and self-efficacy in standing up to prejudice. When considered together, only wellbeing and self-efficacy in standing up to prejudice were significant predictors of self-esteem. This study points to the leverage points that would be worth for further research, to see if engaging in stigma resistance would be associated with higher self-esteem. This was a joint project with another trainee who was assessing the psychometric properties of the WEMWBS-ID and short WEMWBS-ID for individuals with intellectual disabilities.

Part three presents a critical appraisal of the systematic review and empirical paper. The rationale and motivations of this research are discussed. This is followed by reflections on learnings from joint working, the process of recruitment and online data collection in part 2, as well as a discussion on the concept of self-esteem.

Impact Statement

The current thesis informs research and clinical practice in relation to the self-esteem of people with intellectual disabilities. It contains a systematic literature review of studies assessing the self-esteem and links with mental health outcomes of people with intellectual disabilities. The results of this review show that people with intellectual disabilities who participate in social activities tend to have higher self-esteem, which lends support to policies which provide persons with intellectual disabilities with opportunities to engage in a fruitful and meaningful life. Despite the limitations of the current evidence base, the findings from the review suggest that clinicians should be aware of the correlated outcomes of low self-esteem and depression. More research needs to be done in terms of the links between self-esteem and anxiety, and to determine if self-esteem interventions would be helpful in this population.

The second part of the thesis constitutes a cross-sectional study of the predictors of self-esteem in people with intellectual disabilities. Of note to clinicians, not all participants with intellectual disabilities reported low self-esteem. This points to the potential pitfall of assuming people with intellectual disabilities have low self-esteem, and the importance of understanding how they see themselves without making assumptions. Clinicians can then empower people with intellectual disabilities, rather than reinforce stigmatising narratives. In addition, the findings show that wellbeing and self-efficacy in rejecting prejudice are predictors of self-esteem. Further research can be done to examine if interventions in stigma resistance to help people feel more able to stand up to prejudice, could lead to gains in self-esteem and wellbeing.

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Part 1: Literature Review

Self-esteem of adults with intellectual disabilities: A systematic literature review

Abstract

Background: In the general population, low self-esteem has been linked with poorer mental and physical health. Less is known about self-esteem in persons with intellectual disabilities. This systematic literature review aimed to summarise and evaluate the findings of studies that examined levels of self-esteem in persons with intellectual disabilities and links with mental health outcomes.

Method: A systematic search of PsycINFO, Web of Science, and CINAHL was conducted to identify studies published between 1990 and 2021. The studies were appraised using the QualSyst tool. A narrative synthesis was used.

Results: Twenty-six articles were identified of which two studies were removed from the review due to low quality. Studies reported mixed evidence regarding levels of self-esteem compared to the general population. Engagement in activities appeared to be linked with positive self-esteem, and perception of negative interpersonal life events as having a negative impact was associated with lower self-esteem. There was evidence of co-occurrence of low self-esteem and depression, but no studies examined links between self-esteem and anxiety.

Conclusion: The social, occupational, and psychological attributes considered were important to how individuals with intellectual disabilities viewed themselves. However, clear causal links have yet to be identified, and more research is needed using longitudinal designs to answer questions about trajectory.

1. Introduction

Self-esteem is a construct that has been widely studied but is difficult to define. Donnellan, Trzesniewski, and Robins (2011) defined self-esteem as an individual's subjective evaluation of her or his worth as a person. This means that if a person believes that they are of worth or value, then they have high self-esteem, regardless of whether this self-evaluation is validated by others and a person's objective abilities or skills. Rosenberg (1989) conceptualised self-esteem as the feeling that one is good enough, and added that self-esteem involves feelings of self-respect and self-acceptance. Low self-esteem thus implies self-rejection, self-dissatisfaction, and self-contempt. With reference to high and low self-esteem, of note self-esteem is a continuous variable which operates in terms of degree rather than discrete type (e.g. having or not having self-esteem).

Others suggest that self-esteem involves an evaluative component of self-knowledge, serving as an accurate estimate of one's characteristics (Baumeister, Campbell, Krueger, & Vohs, 2003). This implies a need for an external yardstick to determine if the judgements of the self are accurate. However, this leads to difficult questions about the set of values imposed to judge the self as this suggests that there are groups of people who, based on a certain set of values, should not generally have a positive attitude towards themselves. Conversely, the more traditional view of self-esteem suggested by Rosenberg (1989) bypasses the need for an external validity criterion and suggests that a self-report approach to assessing self-esteem is sufficient, given that the gauge of a person's self-worth lies in their self-evaluation.

However, measuring self-esteem using self-report measures lends itself to potential biases. For example, reactivity refers to the extent in which conducting research or measurement in itself causes the factor being studied to change (Heppner, Wampold, Owen, & Wang, 2015). Participants develop expectations and hypotheses about the purpose of studies and may be motivated to behave in ways they believe to be socially desirable. This is relevant to self-report measures of self-esteem, given the typically high face validity of such measures. In addition, asking participants to think about their self-esteem may encourage them to consider their self-esteem in a new way or form an opinion when they previously had none (Levy, 2019). Given concerns over the validity of explicit self-report measures, an alternative is to use implicit measures. One common example is the implicit association test which measures reaction time to assess the degree to which individuals associate themselves with a positive as opposed to a negative concept (Greenwald, McGhee, & Schwartz, 1998). Individuals with high implicit self-esteem will link positive words to themselves faster than negative words, and these associations are assumed to be unconscious given the need for a fast response. However, different implicit measures of self-esteem appear to not correlate highly with each other (Bosson, Swann, & Pennebaker, 2000), and correlations between implicit and explicit self-report measures are generally low and variable (Hofmann, Gawronski, Gschwendner, Le, & Schmitt, 2005). These findings point to problems with the validity of measures of implicit self-esteem. As such, this review focuses on research based on explicit measures of self-esteem.

Nonetheless, research on explicit self-esteem is also often hindered by factors such as biases in self-report measures noted above, and difficulties with establishing cause and effect, which cannot be established from correlational research designs. In addition, factors studied could both be causes and effects of each other. For example, one could argue that higher self-esteem may lead to more popularity in social groups, but being more popular may in turn lead to higher self-esteem. In addition, the problem of multiple causation means that low self-esteem could be caused by multiple interacting factors, and not just one cause (Levy, 2019).

Despite the challenges, studies have examined the basic demographic correlates of self-esteem. Gender effects for self-esteem have been found to be small, with men showing somewhat more positive self-esteem in a meta-analysis by Kling, Hyde, Showers, and Buswell (1999). In particular, the gender difference in self-esteem appeared to be more pronounced in adolescence but relatively trivial throughout most of the lifespan. In terms of ethnic differences, Bachman, O'Malley, Freedman-Doan, Trzesniewski, and Donnellan (2011) found that young

African American men showed somewhat higher self-esteem than young White men. There was a larger, but modest difference between young African American men and young Asian-American men, with young Asian-American men showing lowest self-esteem. The explanations behind these differences, though modest, remain contentious. Bachman et al. (2011) suggested that the differences might be explained in terms of cultural norms and standards for expressing self-esteem. For example, African American youth may be encouraged to express high self-esteem as this may help them cope with discrimination (Hughes et al., 2006), while Asian Americans might be socialised to express humility given the importance of group harmony (Cai, Brown, Deng, & Oakes, 2007).

In terms of the importance of self-esteem, the evidence has been mixed as to whether self-esteem impacts on life outcomes. A qualitative review by Baumeister et al. (2003) concluded that apart from happiness, self-esteem was not a major predictor of life outcomes including school performance, task performance, interpersonal relationships, depression, and antisocial behaviour. However, there were few prospective studies conducted on self-esteem then, and since the review, longitudinal studies have been carried out to investigate the prospective effects of self-esteem. There is now growing evidence on the association between self-esteem and long-term outcomes. Trzesniewski et al. (2006) analysed prospective data from the Dunedin Multidisciplinary Health and Development Study birth cohort and found that adolescents with low self-esteem had poorer mental and physical health, worse economic prospects, and higher levels of criminal behaviour during adulthood, compared with adolescents with high self-esteem. These long-term consequences were found after controlling for gender, socioeconomic status and depression.

The link between low self-esteem and mental health is complex. Fennell (2016) suggested that low self-esteem could be both a vulnerability factor for developing mental health problems, and a consequence of mental health difficulties. This is echoed by a systematic review showing the association between low self-esteem and clinically significant anxiety and depression among young people (Keane & Loades, 2017). Self-esteem may be a buffer against depression or anxiety, or that experiences of depression or anxiety might threaten the self-concept and reduce self-esteem. Evidence from cross-lagged longitudinal studies indicates that self-esteem predicts depression, whereas depression does not predict self-esteem (Orth, Robins, Trzesniewski, Maes, & Schmitt, 2009). More recent evidence has also shown the predictive effects of self-esteem on depression and anxiety (Sowislo & Orth, 2013). Accordingly, low self-esteem can be seen as a vulnerability factor for depression and anxiety, and not simply an alternative indicator.

Despite its importance as a psychological construct and its associations with mental and physical health in the general population, little is known about self-esteem in adults with intellectual disabilities. This population are often subject to abuse, bullying, discrimination and social exclusion (e.g., Beadle-Brown et al., 2014; Brownridge, 2006) and are exposed to more traumatic life events compared to the general population (Hughes et al., 2012). Maiano et al. (2019) reviewed studies published between 1979 and 2017 on the self-esteem of school-aged youth with intellectual disabilities. They found that youth with intellectual disabilities had lower global and domain specific cognitive-academic self-esteem compared to typically developing youth. One Spanish study showed that adults with intellectual disabilities had lower self-esteem and more mental health symptoms than the general population (Garaigordobil & Pérez, 2007), but it is unclear if there is any consensus in the literature.

To my knowledge, no review examining self-esteem in adults with intellectual disabilities has been published. A review of the research conducted in understanding the correlates of self-esteem of adults with intellectual disabilities, and in particular the relationship between self-esteem and mental health outcomes such as depression or anxiety, may help us identify support needs and tailor interventions.

1.1 Aims and Objectives

The review aimed to answer the following questions:

1. What is known about self-esteem in adults with intellectual disabilities?
2. Is there a relationship between low self-esteem and anxiety disorders and/or depression in adults with intellectual disabilities, similar to relationships observed in the general population?

2. Method

2.1 Search Strategy

A systematic search was carried out across the electronic databases PsycINFO, Web of Science, and CINAHL for years covered through September 2021. The terms 'intellectual disabilit*', 'intellect* impair*', 'learning disabilit*', 'learning difficult*', 'mental retard*', 'intellectual development disorder*', 'developmental disorder', 'developmental disabilit*' were combined using Boolean terms with the terms 'self-esteem', 'self-concept', 'self-image', 'self-perception', 'self-confidence', 'self-worth', or 'self-evaluation'. It was considered that many relevant articles to answer the second review question would be found using the search terms above. The review was registered prospectively in Prospero (ID CRD42021272271).

2.2 Inclusion and Exclusion Criteria

Studies were screened for eligibility using the following inclusion criteria. The article had to be a peer reviewed paper, published in English since 1990, reporting a quantitative or qualitative study. Non-original studies (e.g. comments, reviews, theoretical papers), case studies, conference papers and book chapters were excluded.

Participants had to be aged over 16 years old, presenting with intellectual disabilities, determined either based on an IQ score <70 as assessed with standardised tools, significant limitations in adaptive behaviour on adaptive behaviour tests, or administratively defined such as through use of education or health services for people with intellectual disabilities. Studies with participants who had specific learning difficulties (e.g. dyslexia) or other neurodevelopmental disorders (e.g. attention deficit hyperactivity disorder) in the absence of intellectual disabilities were excluded.

Articles were included if the primary purpose was to compare self-esteem of adults with intellectual disabilities and the typically developing population, or to examine the relationship between self-esteem and psychosocial functioning in the intellectually disabled population. Articles were excluded if they only measured one specific domain of self-esteem, for example, using a physical self-esteem measure focused on body concept and physical attributes (e.g. Pan & Davis, 2019). Final judgements on whether articles would be included in the review were made in discussion with the research supervisor.

2.3 Quality assessment

The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Cook, & Lee, 2004) was used for quality assessment of the articles. The QualSyst tool employs a scoring system that aims to provide a systematic, reproducible and quantitative means of simultaneously assessing the quality and reporting of research using a broad range of study designs. A second researcher independently rated all articles. Cohen's κ was computed to determine if there was agreement between the two raters' scores. Apart from one item in the small number of qualitative studies where there was moderate agreement (κ = .500), all other items had substantial to very high agreement (κ = .725 to 1, $p < .001$). Discrepancies were resolved through discussion.

2.4 Data analysis

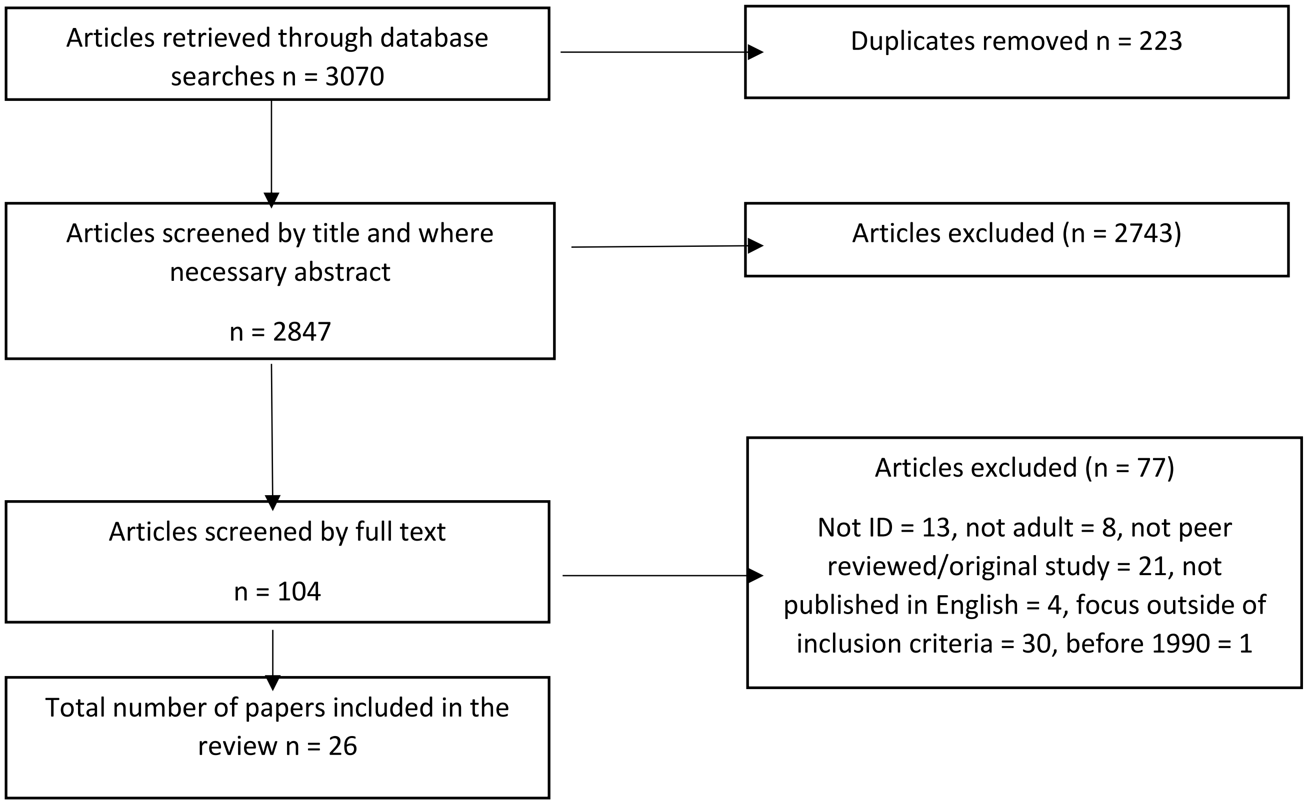
Descriptive information was extracted for each study: author, year, country, overall study aims, study design, data collection (questionnaire measures used), and sample characteristics. To identify findings relating to the aims of the review, the following data was extracted: experiences of self-esteem, experiences of psychosocial functioning relating to self-esteem, experiences of anxiety and/or depression in relation to self-esteem. Key findings were identified through the primary study aims as specified by the paper, themes discussed and identified by the author(s) in the paper, and themes reported which the reviewer identified. Data was synthesised narratively. Meta-analysis was not carried out as most of the studies explored different factors associated with self-esteem.

3. Results

As illustrated in Figure 1, a total of 3070 articles were identified, reduced to 2847 articles after duplicates were removed. The titles and where necessary abstracts were screened. Most of the papers removed in this stage were pertaining to child studies. The remaining 104 full text articles were retrieved and read in full to identify if they met the inclusion criteria. Of these, 26 articles met the inclusion criteria and formed the set of articles for the current review. They reported on 27 separate studies, with one article reporting on two studies (Szivos, 1990), and were conducted mainly in the United Kingdom (n = 14), Australia (n = 5), the United States (n = 3), as well as one each in Canada, France, Hong Kong, Israel, and Spain. Twenty one studies used quantitative methodologies, two used qualitative methodologies, and four studies used mixed methods.

Figure 1

PRISMA diagram illustrating search process



3.1 Quality Rating

The QualSyst (Kmet et al., 2004) tool includes 14 items for quantitative studies and ten items for qualitative studies, relevant to the study type, see Table 1. The QualSyst instructions give an indication of how each criterion should be rated. On each criterion, studies were given a score of 0 = no, 1 = partially met, 2 = yes, or ‘not applicable’. The total quality score was calculated by summing individual item scores and dividing by the sum of the total possible scores.

Table 1

QualSyst criteria for quantitative and qualitative studies

Item Number	Criterion (Quantitative)	Criterion (Qualitative)
1	Question/objective sufficiently described?	Question/objective clearly described?
2	Design evident and appropriate?	Design evident and appropriate?
3	Method of participant selection described and appropriate?	Context for study clear?
4	Participant (and comparison group) characteristics or input variables/information sufficiently described?	Connection to theoretical framework/wider body of knowledge?
5	Random allocation described?	Sampling strategy described, relevant, and justified?
6	Blinding of investigators to intervention reported?	Data collection methods clearly described and systematic?
7	Blinding of subjects to intervention reported?	Data analysis clearly described, complete, and systematic?
8	Outcome well defined and robust to measurement bias? Means of assessment reported?	Use of verification procedures to establish credibility?
9	Sample size appropriate?	Conclusions supported by results?
10	Analysis described and appropriate?	Reflexivity of account?
11	Some estimate of variance reported for main results?	
12	Controlled for confounding?	
13	Results reported in sufficient detail?	
14	Conclusions supported by results?	

Kmet et al. (2004) suggested that out of a possible maximum score of 1, 0.75 represents a relatively conservative and 0.55 a relatively liberal threshold for inclusion. Table 2 shows the quality scores for each article. The quality of the articles was variable, with scores ranging from 0.33 to 0.95, with an average quality score of 0.74. Adopting Kmet et al. (2004)'s liberal threshold, studies that scored below 0.55 were excluded from further review (Barber, Jenkins, & Jones, 2000; Study 2 in Szivos, 1990).

Table 2

Quality ratings using QualSyst criteria for the reviewed studies

Author(s) & date	**Quantitative**															**Qualitative**										
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Overall	1	2	3	4	5	6	7	8	9	10	Overall
Abraham et al. (2002)	2	2	1	2	NA	NA	NA	2	1	1	2	NA	2	2	0.85	-	-	-	-	-	-	-	-	-	-	-
Ajmal (2008)	2	2	1	0	NA	NA	NA	2	1	1	2	0	2	2	0.68	-	-	-	-	-	-	-	-	-	-	-
Barber et al. (2000)	1	0	NA	1	NA	NA	NA	1	NA	NA	NA	NA	0	1	0.33	-	-	-	-	-	-	-	-	-	-	-
Barlow & Kirby (1991)	2	2	1	2	NA	NA	NA	1	1	1	2	0	2	2	0.73	-	-	-	-	-	-	-	-	-	-	-
Benson & Ivins (1992)	2	2	1	2	NA	NA	NA	2	2	1	2	1	2	2	0.86	-	-	-	-	-	-	-	-	-	-	-
Bouvet & Coulet (2016)	2	2	2	2	2	0	NA	2	1	2	2	2	2	2	0.88	-	-	-	-	-	-	-	-	-	-	-
Crawford et al. (2015)	2	2	1	2	NA	NA	NA	2	1	2	2	1	2	2	0.86	-	-	-	-	-	-	-	-	-	-	-
Dagnan & Sandhu (1999)	2	2	1	2	NA	NA	NA	2	1	2	2	NA	2	2	0.90	-	-	-	-	-	-	-	-	-	-	-
Davies et al. (2021)	2	2	2	2	NA	NA	NA	2	2	1	2	0	2	2	0.86	-	-	-	-	-	-	-	-	-	-	-
Esbensen & Benson (2005)	2	2	1	2	NA	NA	NA	2	2	1	2	2	2	2	0.90	-	-	-	-	-	-	-	-	-	-	-
Garaigordobil & Perez (2007)	2	2	2	2	NA	NA	NA	2	1	1	2	0	2	2	0.82	-	-	-	-	-	-	-	-	-	-	-
Gascon (2009)	2	2	2	2	NA	NA	NA	2	1	1	2	2	2	2	0.91	-	-	-	-	-	-	-	-	-	-	-
Griffin et al. (1996)	2	2	0	1	NA	NA	NA	2	2	1	2	0	2	2	0.73	-	-	-	-	-	-	-	-	-	-	-
Jiranek & Kirby (1990)	2	1	1	1	NA	NA	NA	1	1	2	2	0	2	2	0.68	-	-	-	-	-	-	-	-	-	-	-

Author(s) & date	**Quantitative**															**Qualitative**										
Johnson (2012)	2	2	1	2	NA	NA	NA	2	1	2	0	0	2	1	0.68	-	-	-	-	-	-	-	-	-	-	-
King et al. (1999)	1	0	1	2	NA	NA	NA	2	1	1	2	0	2	1	0.59	-	-	-	-	-	-	-	-	-	-	-
Li et al. (2006)	1	2	1	2	NA	NA	NA	1	2	2	2	0	2	2	0.77	1	2	1	2	0	2	1	2	2	0	0.65
MacMahon & Jahoda (2008)	2	2	2	2	NA	NA	NA	2	1	2	2	1	2	2	0.91	-	-	-	-	-	-	-	-	-	-	-
Mahoney-Davies et al. (2017)	1	2	1	2	NA	NA	NA	2	1	2	2	1	1	2	0.77	-	-	-	-	-	-	-	-	-	-	-
McGillivray & McCabe (2007)	2	1	2	2	NA	NA	NA	2	2	1	2	2	2	2	0.91	-	-	-	-	-	-	-	-	-	-	-
Neuman & Reiter (2017)	2	2	0	2	NA	NA	NA	2	2	2	2	2	2	2	0.91	2	2	1	2	1	2	2	0	2	0	0.70
Paterson et al. (2012)	2	2	1	2	NA	NA	NA	2	2	2	2	NA	2	2	0.95	-	-	-	-	-	-	-	-	-	-	-
Pestana (2015)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	2	2	1	2	1	1	2	2	2	0	0.75
Petrovski & Gleeson (1997)	2	2	1	1	NA	NA	NA	2	1	1	1	0	2	1	0.64	2	2	2	1	1	2	0	0	1	0	0.55
Szivos (1990) – Study 1	1	1	1	1	NA	NA	NA	1	1	1	0	0	2	2	0.55	-	-	-	-	-	-	-	-	-	-	-
Szivos (1990) – Study 2	1	1	1	0	NA	NA	NA	1	1	2	0	NA	2	2	0.55	1	1	2	1	1	1	0	0	2	0	0.45
Whelan et al. (2007)	0	1	NA	2	NA	NA	NA	2	NA	NA	NA	NA	NA	1	0.60	-	-	-	-	-	-	-	-	-	-	-

Across the quantitative and mixed method studies, most fully met the quality standards for the following: description of study question, study design and participant characteristics, outcome measures defined, estimate of variance reported, results reported in sufficient detail, and conclusions supported by the results. The quality of the reporting of studies was weaker in terms of method of participant selection, having an appropriate sample size, and description and appropriateness of the analytic methods used. Only two studies fully met the quality standard for describing their method of participant selection as well as their analytic methods (Bouvet & Coulet, 2016; MacMahon & Jahoda, 2008). Most studies were surveys, so random allocation to treatment group, as well as blinding of investigators and participants, were not applicable. In addition, some studies could not be assessed on the criterion of controlling for confounds as they were cross-sectional surveys of a single group.

Considering the qualitative studies, quality of reporting of the studies was high in terms of description of study design and data collection method. The quality of the studies was low in terms of description of the context of the study, sampling strategy, and use of verification procedures. Notably, no evidence of reflexivity was noted in any of the papers.

3.2 Sample characteristics and recruitment

Participants were recruited from community organisations working with individuals with intellectual disabilities (e.g. day centres, vocational or housing agencies) (n = 23), specialist mental health services (n = 4), special schools or colleges (n = 3). Some studies recruited from more than one source. Three studies included a sample of participants without intellectual disabilities, recruited through convenience sample of existing databases or through social media.

3.3 Measurement of self-esteem

The studies measured self-esteem using self-report measures designed for the general population or for children, with adaptations for the sample of individuals with intellectual disabilities. The most commonly used measure was the Rosenberg Self-esteem Scale

(Rosenberg, 1965). Previous research has reported adequate levels of internal consistency when used with the general population with Cronbach's α of 0.72 to 0.88 (Byrne, 1996) and test-retest correlation of 0.85 (Silber & Tippett, 1965). Of the studies reviewed, one did not report any adaptations to the original 10-item scale using a 4-point response scale (Garaigordobil & Perez, 2007), while most other studies reported using adapted versions. Mahoney-Davies et al. (2017) and Whelan et al. (2007) used simplified wording. Ajmal (2008) as well as Jiranek and Kirby (1990) had participants agree or disagree to the items, while Crawford et al. (2015) included pictorial representations of response items. These papers did not report on the psychometrics of the scale following their adaptations. Dagnan and Sandhu (1999) adapted the scale to a 6-item version, with simplified wording and added a 5-point response scale with visual cues, reporting Cronbach's α of 0.62 and test-retest correlation of 0.68 for the adapted scale. This adaptation was used in five other studies (Davies et al., 2021; Johnson, 2012; MacMahon & Jahoda, 2008; McGillivray & McCabe, 2007; Paterson et al., 2012). A French version with good internal reliability, with Cronbach's α of 0.83 to 0.90 (Vallieres & Vallerand, 1990) was used by Bouvet and Coulet (2016) and Gascon (2009).

The Szivos-Bach (1993) 24-item Self-esteem Index with a 6-point response scale was used in two studies (Abraham et al., 2002; Petrovski & Gleeson, 1997). While no reliability index was reported by Petrovski and Gleeson (1997), Abraham et al. (2002) reported that in their sample the measure showed very good reliability with a Cronbach's α of 0.90 and test-retest correlation of 0.66.

Neuman and Reiter (2017) used a Hebrew translation of the 100-item Tennessee Self-concept Scale Second Edition (Fitts & Warren, 1996), with the response reduced from a 5-point to a 3-point scale. For their sample they reported Cronbach's α of 0.90 for the total self-esteem score (Neuman & Reiter, 2017). Griffin et al. (1996) and King et al. (1999) used the 25-item Coopersmith (1981) Self-esteem Inventory, with the former re-wording the response options to "yes/no" instead of the original "like me/not like me". While the original Coopersmith Self-esteem Inventory has a Cronbach's α of 0.68 to 0.77 when used with the general population (Coopersmith, 1981), Griffin et al. (1996) and King et al. (1999) did not report on reliability of the measure when used with participants with intellectual disabilities. The Chinese version of the Adult Source of Self-esteem Inventory (Tam & Watkins, 1995) which uses a 10-point rating scale on 40 items was used by Li et al. (2006). While Li et al. (2006) did not report on the reliability of the measure in their sample, they noted that when the measure was validated with Hong Kong Chinese adults, it showed high reliability with Cronbach's α of 0.92 (Tam & Watkins, 1995).

Of note, two studies used a self-esteem measure that was originally designed for use with children. Esbensen and Benson (2005) adapted the 80-item Piers-Harris Self-esteem Questionnaire (Piers, 1984) by altering items referring to school to refer to work, but kept the yes/no response scale. Benson and Ivins (1992) adapted the 40-item, yes/no response McDaniel-Piers Young Children's Self-concept Scale (McDaniel, 1973) by removing items which referred to siblings or did not have obvious workplace equivalents. Esbensen and Benson (2005) reported that their adapted measure had Cronbach's α of 0.87, but Benson and Ivins (1992) did not report on the reliability of their adapted measure. Nonetheless, Benson and Ivins (1992) had informants complete five items from the self-report scale, as a measure of the concurrent validity of the self-report measure.

Barlow and Kirby (1991) used an adaptation of the Satisfaction Questionnaire of the Community Adjustment Scale (Seltzer & Seltzer, 1976), with the self-esteem section consisting a set of 14 items on a 2-point scale on self-esteem. There was no reference to reliability of the measure.

Semi-structured interviews were conducted in four studies (Li et al., 2006; Neuman & Reiter, 2017; Pestana, 2015; Petrovski & Gleeson, 1997).

3.4 Overview of Findings

The main findings of the studies are summarised below in relation to the questions guiding this review. See Table 3 for details of included studies.

3.4.1 What is known about the self-esteem of adults with intellectual disabilities?

There were 18 studies relevant to the first research question.

3.4.1.1 Domains of self-esteem

Among adults with intellectual disabilities in Hong Kong, Li et al. (2006) found that the family and social self were important to how participants viewed themselves, which appeared to be in line with Hong Kong culture which has roots in collectivist Chinese culture. In the UK, Pestana (2015) interviewed eight adults with mild intellectual disabilities, exploring the different domains of how they viewed themselves. Most participants identified positive social, occupational, and psychological attributes such as being friendly, helpful, creative, and independent. Nonetheless, some participants reported feeling “not normal” and having physical limitations. The quality rating of these studies was between 0.65 and 0.77, indicating medium quality.

3.4.1.2 Levels of self-esteem in participants with intellectual disabilities compared to the general population

In view of Maiano et al.’s (2019) review concluding that self-esteem was lower in youth with intellectual disabilities than their typically developing peers, one might expect similar findings in adults. Several studies sought to compare self-esteem in adults with intellectual disabilities to the general population, with mixed results. Li et al.’s (2006) Hong Kong study found that participants with intellectual disabilities had more positive self-concepts than the comparison group of people without disabilities. They posited that this might be due to almost 75% of the participants with intellectual disabilities in this study having attended special education and segregated vocational settings. Accordingly, in-group comparisons were likely

Table 3

Summary of studies

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
Abraham et al. (2002), UK	Cross sectional	Community participation	50 adult participants from day centres (28 women, 22 men), participants were split into older (aged 48 – 65) and younger group (aged 23 – 35) by top and bottom age quartiles.	Self-esteem Index. Also measured community participation, stigma and social support.	Higher self-esteem associated with lower perception of stigma. Age moderated relationship between community participation and self-esteem.
Ajmal (2008), UK	Cross sectional, between groups	Forensic population	79 men with ID detained under Mental Health Act, 30 men using community mental health service with mild ID	Rosenberg Self-esteem scale. Also completed mental health measure.	Forensic sample had higher self-esteem than community sample. Self-esteem negatively correlated with mental health.
Barlow & Kirby (1991), Australia	Cross sectional, between groups	Accommodation	31 adults with mild ID: 16 living in residential institution (10 women, 6 men), 15 living in community (5 women, 10 men). Matched in age.	Self-esteem measured using questions developed from a section of the of the Satisfaction Questionnaire of the Community Adjustment Scale. Also measured satisfaction with residential situation, leisure, training, work, finances, interpersonal relationships, future aspirations, and locus of control.	Self-esteem close to maximum score, no significant difference between institutionalised and community participants.

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
Benson & Ivins (1992), USA	Cross sectional	Mood	130 adults with ID living in community (67 women, 63 men), drawn from community agencies providing vocational and residential services. Informants were vocational/residential supervisors who knew person for at least 3 months, family member, or case manager	McDaniel-Piers Young Children's Self-Concept Scale, informant scale composed of 5 items from self-report scale. Also measured anger and depression.	Individuals with higher depression scores tended to report lower self-esteem. Informants tended to rate self-esteem and depression similar to self-report, but self-report and informant ratings of anger not correlated.
Bouvet & Coulet (2016), France	Randomised Controlled Trial	10 weeks relaxation group for anxiety and emotional regulation issues	30 participants with mild to moderate ID (16 women, 14 men), randomised to intervention and control group	Measures at pre- and post-intervention: French version of Rosenberg Self-esteem scale. Also measured emotional regulation and anxiety.	At baseline, self-esteem found to be within norm of general population. Self-esteem increased following intervention in relaxation group, and was higher than control group.
Crawford et al. (2015), UK	Cross sectional	Sport	101 participants (44 women, 57 men) participants from 3 groups: involved in sports via Special Olympics (SO), involved in sport but not via SO, not involved in sports	Rosenberg Self-esteem scale. Also measured stress, social networks, and quality of life.	Association between involvement in SO and reduced stress, increased quality of life, and higher self-esteem. Participation in sports was associated with higher levels of self-esteem.

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
Dagnan & Sandhu (1999), England	Cross sectional	Mood	43 participants (18 women, 25 men) from 4 adult training centres (ATCs). 24 lived with family, 12 in group home, 3 independently, 2 with foster family, 2 not known.	Rosenberg self-esteem scale. Also measured depression and social comparison.	Psychometric analysis of adapted Rosenberg self-esteem scale, which was found to have good internal reliability. No differences in self-esteem based on gender, type of accommodation, or ATC attended. Self-esteem negatively correlated with depression, and positively with social comparison. Total self-esteem correlated with total social comparison score.
Davies et al. (2021), UK	Cross sectional, between groups	Adverse interpersonal experiences	47 people with ID (29 women, 18 men) recruited from community ID teams, higher education colleges, and voluntary organisations and 50 comparison sample without disabilities (36 women, 14 men), matched on age, gender, and ethnicity.	Rosenberg Self-esteem scale. Also measured perceived social support, self-compassion and shame.	People with ID did not report greater number of adverse interpersonal experiences prior to age 18 than controls, but greater impact. People with ID reported higher levels of self-esteem than controls.
Esbensen & Benson (2005), USA	Cross sectional, between groups	Mood	73 adults with ID, of these 12 (6 women, 6 men) with major depression and 12 adults with ID and no psychiatric diagnosis (6 women, 6 men), matched on gender, age, level of ID.	Piers-Harris Children's Self Concept Scale. Also measured depressive symptoms, attributional styles, automatic thoughts, and hopelessness.	Adults with ID and depression displayed lower self-esteem, more negative automatic thoughts, less positive attributional styles. Individuals diagnosed with major depression reported lower self-esteem.

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
Garaigordobil & Perez (2007), Spain	Cross sectional, between groups	Mood	42 users of ID organisation that facilitates integration of people with mild ID (9 women, 33 men), 128 comparison sample with no ID matched in age.	Rosenberg Self-esteem Scale. Also measured psychological distress.	Individuals with ID showed lower self-esteem and more distress compared to control sample.
Gascon (2009), Canada	Cross sectional, between groups	Work	27 adults with mild ID in regular work environment (15 women, 12 men) and 28 in sheltered workshops (17 women, 11 men). Matched on age, sex, marital status and revenue.	Rosenberg Self-esteem Scale French modified version. Also measured loneliness in the workplace.	No differences in self-esteem between samples. People with ID integrated in regular work environment felt lonelier than those working in sheltered work place.
Griffin et al. (1996), USA	Cross sectional, between groups	Work	2 groups of 100 individuals with mild ID each who attended either sheltered workshop settings (43 women, 57 men) or supported employment programmes (25 women, 75 men)	Coopersmith Self-esteem Inventory. Also measured job satisfaction and place of residence.	Participants in supported employment scored higher in self-esteem than those in sheltered workshops. Those living in semi-independent settings showed highest self-esteem, and those living with families scored lowest.

Author (year), country	**Design**	**Focus**	**Sample**	**Measure of Self-esteem**	**Key findings**
Jiranek & Kirby (1990), Australia	Cross sectional, between groups	Work	44 adults with ID: 14 unemployed (7 women, 7 men), 15 employed in sheltered workshop (7 women, 8 men), 15 employed in community (5 women, 10 men). Comparison group of 29 adults without disabilities matched by gender and job: 14 unemployed (7 women, 7 men), 15 employed (5 women, 10 men)	Rosenberg Self-esteem Scale. Also measured job satisfaction, social activities, and negative moods.	Adults with ID in community and sheltered employment had higher self-esteem than those who were unemployed.
Johnson (2012), UK	Cross sectional	Forensic	44 men with mild to borderline ID in secure forensic hospital	Rosenberg Self-esteem scale	Majority had moderate to high self-esteem. No difference in self-esteem by offence type (sexual, fire setting, violent).
King et al. (1999), Australia	Repeated measures	Cognitive behavioural therapy intervention for anger control	11 adults with mild ID (4 women, 7 men), referred for anger problems	Measures at pre-, post-treatment and 12-week follow-up: Coopersmith Self-esteem Inventory. Also measured self- and caregiver-reported anger control, and caregiver-reported emotional and behavioural difficulties.	Increases in self-esteem found from pre- to post, and pre- to follow up.
Li et al. (2006), Hong Kong	Mixed methods	Domains of self-esteem	135 adults with ID (70 women, 65 men), 146 (unmatched) comparison group without disabilities (88 women, 58 men).	Chinese version of Adult Source of Self-Esteem Inventory and interview	Adults with ID showed higher total self-concept scores than control group. Family and social self were important to self-concepts.

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
MacMahon & Jahoda (2008), Scotland	Cross sectional, between groups	Mood (depressed vs not)	18 participants with ID and depression (10 women, 8 men) recruited through specialist mental health services. 18 gender matched participants with ID and no depression recruited through day centres.	Rosenberg Self-esteem scale. Also measured depression and social comparison.	Depressed participants reported more negative social comparisons than non-depressed participants when comparing self to both a general other target and to identified real-world target. High levels of self-esteem associated with low levels of depression.
Mahoney-Davies et al. (2017), UK	Repeated measures	10 week skills group aiming to improve wellbeing	12 participants with ID (1 woman, 11 men) attending day centre	Measures at pre-, mid-, and post-intervention: Rosenberg Self-esteem Scale. Also measured mental wellbeing, and questionnaire designed by authors to measure implementation of skills taught.	Scores on self-esteem and wellbeing were within normal range at baseline, no significant increase post-intervention.
McGillivray & McCabe (2007), Australia	Cross sectional, between groups	Mood	151 participants with mild to moderate ID (68 women, 83 men), recruited through vocational and supported employment services	Rosenberg Self-esteem Scale. Also measured depression, social support, social comparison, and automatic negative statements about the self.	Negative association between social comparison and symptoms of depression, and self-esteem and symptoms of depression.
Neuman & Reiter (2017), Israel	Mixed methods	Intimate relationships	80 participants with mild to moderate ID living in supported living (40 women, 40 men). Half of sample lived in intimate relationship for > a year, matched by gender and age.	Tennessee Self-Concept Scale 2nd ed. translated into Hebrew. Also conducted semi-structured interviews and measured quality of life.	Qualitative study suggested that people with ID in intimate relationships showed positive self-esteem. Quantitative study suggested that people in intimate relationships had higher self-esteem compared to those who had close friends but no intimate relationship.

Author (year), country	Design	Focus	Sample	Measure of Self-esteem	Key findings
Paterson et al. (2012), UK	Cross sectional	Stigma	43 participants with ID (25 women, 18 men) recruited from community centres	Rosenberg self-esteem scale. Also measured stigma perception and social comparison.	Greater perception of stigma related to lower self-esteem. More negative social comparisons with service user and community groups, lower reported self-esteem.
Pestana (2015), UK	Qualitative interview, analysed using interpretative phenomenological analysis	Domains of self-esteem	8 adults with mild ID (2 women, 6 men)	Semi-structured interview	Explored domains of self-esteem including social, physical, occupational, cultural, and psychological aspects. Participants reported mainly positive attributes of themselves in social, occupational and psychological domains. Negative attributes in physical domain, neutral attributes in cultural domain.
Petrovski & Gleeson (1997), Australia	Mixed methods	Work	31 workers with mild ID (16 women, 15 men)	Self-esteem Index and semi-structured interviews. Also measured job satisfaction, stigma, loneliness, and life aspirations.	Workers with most job satisfaction felt least stigmatised and less lonely at work. No relationship between job satisfaction and self-esteem. No significant difference between men and women in job satisfaction, self-esteem, stigma, or aspirations.
Szivos (1990), UK	Cross sectional, between groups	Work	26 participants with ID in further education courses (14 women, 12 men), 24 in work placement course (6 women, 18 men).	Constructed own self-esteem questionnaire. Also measured experiences of stigma and life aspirations.	High self-esteem related to high aspirations in life, but self-esteem not related to age, gender, or type of placement.
Whelan et al. (2007), UK	Repeated measures	Cognitive behaviour therapy intervention to improve self-esteem	5 participants with ID and poor self-esteem (3 women, 2 men) as reported by carers	Rosenberg Self-esteem Scale	Inspection of descriptive data showed that of 5 participants, 2 showed increase in self-esteem, 3 no change.

used to enhance their self-concept. In the UK, Davies et al. (2021) found that their sample of participants with intellectual disabilities recruited from community intellectual disability teams, colleges, and voluntary organisations reported higher levels of self-esteem than the control participants. Conversely, Jiranek and Kirby (1990) Australian sample drawn from employment agencies and sheltered workshops, as well as Garaigordobil and Perez (2007) Spanish sample drawn from a public organisation found that the levels of self-esteem of the group with intellectual disabilities were lower than those in the general population group.

The quality ratings of the studies were moderate with an average of 0.74. However, in all studies, matching of the target sample with a comparison general population sample was either not done or fraught with difficulties. Comparison groups were not matched on key demographic variables such as age, gender, and ethnicity (Garaigordobil & Perez, 2007; Li et al., 2006), the influence of which on self-esteem is admittedly unclear. Most participants in the comparison sample tended to have higher education and occupation levels (Davies et al., 2021; Garaigordobil & Perez, 2007; Li et al., 2006), as one would expect by virtue of one group having intellectual disabilities, though there was an attempt to match the comparison group in terms of education and occupation levels in Jiranek and Kirby (1990)'s study. Overall, it remains difficult to draw conclusions regarding comparisons between levels of self-esteem in people with intellectual disabilities and the general population. Accordingly, and in view of the apparent importance of self-esteem further research is warranted.

The two studies conducted with adults with intellectual disabilities in forensic settings (Ajmal, 2008; Johnson, 2012) concluded that self-esteem in this population was moderate to high, with scores even higher than in community samples. While both papers suggest that this could be in part due to the relatively safe supportive environment, it has to be acknowledged that participants were held for treatment and rehabilitation and could have presented themselves in a more compliant and positive light in order to be seen to be doing well. Quality ratings of these two studies were moderate (0.68). However, of note there was no report on how the community sample was matched (Ajmal, 2008), and the conclusion that the self-esteem levels were moderate to high in Johnson (2012) was not based on any statistical comparison, but on a cut off score decided by the author.

3.4.1.3 Factors relating to self-esteem

The reviewed studies suggested that the more individuals are engaged in life and activities around them, the higher their self-esteem. For example, individuals who participated in the Special Olympics or general sports tended to show higher self-esteem than those who were not involved in sports (Crawford et al., 2015). In another study, individuals with mild intellectual disabilities involved in an intimate relationship had more positive self-esteem than those with only close friend relationships (Neuman & Reiter, 2017). According to people with intellectual disabilities, involvement in an intimate relationship was found to be meaningful in providing company, intimacy, partnership for life, and plan the future with. The quality of these studies was generally high, with an average rating of 0.82.

Similarly, engagement in work was associated with higher self-esteem. Individuals with intellectual disabilities engaged in employment showed higher self-esteem than those who were unemployed (Jiranek & Kirby, 1990). Results were mixed when comparing the types of employment individuals engaged in (Gascon, 2009; Griffin et al., 1996; Szivos, 1990), but they proposed that regardless of work environment, being able to work, having contact and support from other people, and belonging to a group may contribute to higher self-esteem. These studies had generally good quality ratings, averaging 0.72. Their conclusions were echoed by Abraham et al. (2002), Paterson et al. (2012), and Petrovski and Gleeson (1997), in that self-esteem was linked with feeling non-stigmatised and valued.

Results were mixed in terms of the link between independent living and self-esteem. In one study, higher independence in living environment was linked with higher self-esteem (Griffin et al., 1996). Individuals who were responsible for their activities of daily living and had choice over how to spend their time showed higher self-esteem than those whose lives were closely supervised. However, this conclusion needs to be treated with caution as groups were not matched on any demographic variables, meaning that differences in self-esteem may not necessarily be due to different living arrangements. Contradictory findings were found in Barlow and Kirby (1991), who observed no differences in self-esteem between participants living in the community and those living in an institution with less independence. Nonetheless, this study only included participants from one particular institution, which suggests that findings are unlikely to be generalisable. More research is warranted to establish the potential effects of independence in living environments on self-esteem. Both studies had similar quality ratings of 0.73.

Interestingly, one study suggested that age moderated the effect of participating in the community on self-esteem (Abraham et al., 2002). When comparing the top and bottom age quartiles of their participants, they found that frequent activities were associated with higher self-esteem in the older group, but with lower self-esteem in the younger group. While the study did not indicate if there were other differences in the types of activities engaged in between the groups, they noted a negative correlation between activities with peers and self-esteem in the younger group (Abraham et al., 2002). One possible hypothesis is that younger adults could be more sensitive to comparisons with others, which may be inadvertently occurring in peer activities. This suggests that younger adults with intellectual disabilities may need more support in interpreting and managing their social experiences.

In terms of negative life experiences, the number of perceived negative interpersonal life events perceived as having a negative impact was proposed as having a predictive effect on self-esteem, mediated by shame and self-compassion (Davies et al., 2021). Although this study relied on self-reported negative interpersonal life events before the age of 18, which can be a difficult task for adults with intellectual disabilities to reliably do, the results point to the importance of building up self-compassion and reducing shame, in reducing the relationship between the number of perceived negative interpersonal life events and self-esteem.

3.4.1.4 Response to intervention

Four intervention studies were included in the review, of which only one (Whelan et al., 2007) had a specific focus on improving self-esteem while the others included self-esteem as an outcome measure following skills training on wellbeing (Mahoney-Davies et al., 2017), relaxation (Bouvet & Coulet, 2016), and managing anger (King et al., 1999). Crucially, most studies were very small in scale and did not include a control group. Of note, one study did not run statistical analyses on outcome measures, and only relied on descriptive observations of scores (Whelan et al., 2007). In addition, for the study which included the control (Bouvet & Coulet, 2016), it is unclear if the group gains were made due to specific elements in the intervention, as the controls were not engaged in any activity. Gains may be due to common group factors such as the opportunity to meet regularly, rather than the specific intervention. Together, results remain inconclusive if self-esteem can be improved with intervention. Larger scale studies with proper control groups would need to be conducted.

3.4.2 Question 2: Is there a relationship between low self-esteem and depression and/or anxiety disorders?

Individuals with intellectual disabilities appear to show higher levels of psychological distress when compared to the general population (Garaigordobil & Perez, 2007; McGillivray & McCabe, 2007), with one study identifying 39.1% of a community sample as displaying symptoms of depression (McGillivray & McCabe, 2007). The reviewed studies presented consistent results that individuals with intellectual disabilities who have low self-esteem tend to be more vulnerable to depression (Benson & Ivins, 1992; Dagnan & Sandhu, 1999). A similar pattern was found in studies involving samples of individuals with intellectual disabilities who met criteria for clinical depression (Esbensen & Benson, 2005; MacMahon & Jahoda, 2008).

In particular, it appears that social comparison may be an important dimension in predicting depression (Dagnan & Sandhu, 1999). Those who were depressed tended to make more negative social comparisons than non-depressed individuals (MacMahon & Jahoda, 2008).

In one study, social comparison and low self-esteem distinguished between individuals who were deemed to be at risk, or met criteria for depression, from those who did not (McGillivray & McCabe, 2007).

However, one major limitation of the findings is that all studies were cross sectional in design, which means that causality cannot be concluded. In addition, two studies used measures designed for children, and the adapted versions used were not validated for an intellectual disability population or had poor internal consistency (Benson & Ivins, 1992; Esbensen & Benson, 2005). Comparisons made between individuals with and without depression were based on unmatched participant groups (Garaigordobil & Perez, 2007; MacMahon & Jahoda, 2008). Therefore, further study into the nature and development of the relationship between self-esteem and depression is warranted.

4. Discussion

4.1 Key findings

The results from the 25 studies included in this review indicate that the social, occupational, and psychological attributes considered were important to how individuals with intellectual disabilities view themselves. Findings on levels of self-esteem among individuals with intellectual disabilities as compared to the general population were mixed and preliminary evidence suggests moderate to high self-esteem among individuals with intellectual disabilities in forensic settings compared to individuals in the community. Comparatively, school-aged youth with intellectual disabilities appear to have lower self-esteem than typically developing youth (Maiano et al., 2019). One explanation could be that school-aged youth are more sensitive to social comparisons with their peers, and have compared themselves with peers who may be doing better academically in school. Such social comparisons may be less salient for adults and the social groups they choose to partake in. Nonetheless, it is noted that the conclusions from the studies reviewed are based on comparisons with unmatched samples and as such are inconclusive.

Despite evidence from the general population that sociodemographic variables such as age and ethnicity predict self-esteem (Bachman et al., 2011; Kling et al., 1999), this has not been found in individuals with intellectual disabilities.

In general, engagement in activities appeared to be linked with positive self-esteem. Increased participation in activities likely provided individuals with opportunities to be independent, experience achievement and mastery. This is in line with findings from the general population. For example, engagement in sports and extracurricular activities has been found to be positively linked with self-esteem (Williams & McGee, 1991). Participation in activities leads to engagement in wider social networks, adding to the psychological wellbeing and perceived competence of the participant (McGee, Williams, Howden-Chapman, Martin, & Kawachi, 2006). While results were inconclusive in terms of association between living situation and self-esteem, firmer results were found with regards to occupation in meaningful work. Regardless of work environment, the reviewed evidence suggests that being able to work, have contact with other people, and feel valued may contribute to higher self-esteem. This importance of feeling valued and non-stigmatised links to the conceptual model of the relationship between stigma and self-esteem, whereby those who are aware of being viewed negatively by others because they belong to a stigmatised group will incorporate negative social attributions into their sense of self, resulting in lower self-esteem (Crocker & Major, 1989).

In addition, the perception of negative interpersonal life events as having a negative impact was associated with lower self-esteem. Individuals with high shame and low self-compassion tended to have lower self-esteem. This is consistent with the general literature on the mediating effects of shame, and the clinical implications of working with a compassion-focused therapy framework (Shorey et al., 2010). However, the studies reviewed that looked into improving self-esteem through interventions were generally small scale and did not have a control group.

Evidence for the co-occurrence of low self-esteem and depression in individuals with intellectual disabilities was found. This is in line with previous findings on the general population (Keane & Loades, 2017). In addition, a meta-analysis on studies in the general population found (a) consistent support for the vulnerability model of low self-esteem and depression, according to which negative evaluations of the self are a causal risk factor of depression, and (b) weak support that low self-esteem is a consequence of depression (Sowislo & Orth, 2013). Of note, none of the studies reviewed examined the link between anxiety and low self-esteem. In the general population however, a large body of studies has demonstrated the relationship between low self-esteem and symptoms of anxiety and found negative, medium to strong correlations (Lee & Hankin, 2009; Sowislo & Orth, 2013). Further research investigating if these relationships hold true for individuals with intellectual disabilities is warranted.

4.2 Limitations of the review

Limitations of this review include using relatively narrow search parameters. Only studies published in English were included, and dissertations and non-published studies were excluded to ensure quality control from the outset. In addition, to limit the number of studies found, studies tagged with keywords involving children were excluded at the search phase. This may have resulted in studies being unduly removed.

4.3 Limitations of the evidence

There are several limitations to the evidence presented in this review. First, 23 out of the 25 studies were conducted in predominantly White Western societies. The other two studies were from Hong Kong and Israel. It is difficult to determine if the findings would be replicable in other settings, especially considering that feeling 'good enough' involves some level of comparison and self-evaluation (Rosenberg, 1989), and that different societies value different domains of self, as shown in this review.

Secondly, most of the studies reviewed relied on administrative definitions of intellectual disability, and did not document if participants had other comorbid conditions which may well affect self-esteem (e.g. physical or sensory disabilities or autism spectrum disorders). Therefore, it is not possible to conclude if findings might differ for different groups, and if additional comorbidities might account for some of the discrepancies in the results. In addition, most studies did not account for the potential confounding effects of differences in cognitive and adaptive functioning, or communication abilities, which could well affect social interactions and opportunities available to the individual, and the meaning the individual attributes to their experiences.

Thirdly, as noted earlier, most of the studies were cross-sectional in nature. Therefore, conclusions cannot be made about causality, or trajectories of self-esteem or depression. In addition, the reviewed studies used a range of questionnaires to measure self-esteem. While some of the authors demonstrated the use of psychometrically sound questionnaires, many did not. Of note, many studies made adaptations to the measures used, while others did not and/or used scales originally developed for children.

In addition, public and patient involvement (PPI) was not part of this review. While PPI is recommended at any or all stages of a review in order to ensure that the review is relevant and meaningful (Shokraneh & Adams, 2018), this was not carried out in the current review due to time and resource constraints.

4.4 Implications for future practice and research

Following from the limitations identified, more research should be conducted in diverse world regions and cultures. Nonetheless it is acknowledged that more evidence may be presently available, but may have been overlooked due to this review's limitations of only including studies reported in English. It is also recommended for research to report more on participants' sociodemographic characteristics including any comorbid conditions that could potentially relate to differences in cognitive and adaptive functioning or communication abilities, and for studies of a longitudinal nature to be able to answer questions about trajectory and causality. Further studies to develop and establish psychometrically sound questionnaires on self-esteem should be done. At minimum, studies should report on the validity and reliability of the measures used.

Nonetheless, the evidence reviewed highlights that although clear mechanisms have yet to be identified, the associations between self-esteem and variables such as participation in social activities for persons with intellectual disabilities are similar to the general population. This lends support to educational and societal policies that seek to provide persons with intellectual disabilities with opportunities to engage in a meaningful life. However, it is of note that the picture is not straightforward; clinical practice and service delivery generally has to be done in a person-centred, individual manner, given the variability in the findings presented.

In addition, the co-occurrence of low self-esteem and depression, though it does not confirm that low self-esteem predates depression, points to the importance of clinicians being mindful of these two correlated outcomes. It is noteworthy that no studies were found that examined the link between self-esteem and other internalising disorders such as anxiety. It is crucial for further research to better understand correlates of self-esteem, and to understand if people with intellectual disabilities will benefit from interventions on self-esteem. After all, psychological interventions for the general population have seen benefits in enhancing self-esteem, for healthy, depressed, or anxious individuals, with medium to large effect sizes for cognitive behavioural therapy (Kolubinski, Frings, Nikčević, Lawrence, & Spada, 2018), and small effect sizes for reminiscence-based interventions (Pinquart & Forstmeier, 2012).

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Part 2: Empirical Paper

What predicts self-esteem of individuals with intellectual disabilities?

Abstract

Background: Literature in the general population shows links between self-esteem, sociodemographic characteristics, and positive life outcomes. Apart from how people with intellectual disabilities might respond to stigma in terms of internalising the negative views or focusing on more positive views of themselves, little is known about the predictors of self-esteem in this population.

Method: This study used a non-experimental, correlational, cross-sectional design. There was a total of 96 participants, of which 44 were recruited for the purposes of this study and 52 were recruited for the purposes of previous projects. Participants had mild to moderate intellectual disabilities, and were recruited via social media and third sector voluntary organisations. The study was conducted online via a videocall.

Results: Results indicate that none of the sociodemographic characteristics were significant predictors of self-esteem. Higher levels of self-esteem were associated with higher levels of wellbeing, sense of social power, and self-efficacy in rejecting prejudice. Wellbeing and self-efficacy in rejecting prejudice were significant predictors of self-esteem.

Conclusions: The lack of association between sociodemographic characteristics and self-esteem was in contrast with findings from the general population, possibly due to the differences in developmental trajectories and opportunities to take on socially valued roles in both populations. The links between self-esteem, wellbeing, and self-efficacy in rejecting prejudice are in line with the larger body of stigma research. Clinicians are encouraged to not assume that adults with intellectual disabilities have low self-esteem, and to support people to advocate for themselves within the public realm.

1. Introduction

Interest in positive mental health and its contribution to quality of life has been increasing. This emerging focus on positive mental health is aligned to a health promotion perspective which focuses on positive health rather than illness and the development of a wellbeing policy agenda (Barry, 2009). Positive mental health refers to attributes such as an helpful perception of reality, self-knowledge, voluntary control over behaviour, self-esteem, self-acceptance, ability to form affectionate relationships, and be productive (M. Jahoda, 1958; Keyes, 2005; Trompetter, de Kleine, & Bohlmeijer, 2017).

The World Health Organisation (2001) defines positive mental health as a state of wellbeing in which the individual realises their abilities, copes with the normal stressors of life, is productive and fruitful, and makes a contribution to their community. This definition points to the idea that positive mental health is not simply the opposite of mental ill-health. This is backed by research from Keyes (2005) that positive and negative wellbeing are independent, suggesting that mental health and mental ill-health are on distinct, though correlated axes. The absence of mental disorders does not equate to the presence of positive mental health, and individuals without mental disorders may experience a range of degrees of positive mental health. Furthermore, as Kovess-Masfety, Murray, and Gureje (2005) point out, the understanding of positive mental health is likely to be influenced by a culture's values, norms, and beliefs about health and illness.

Among the general population, research has revealed that people who look more positively at their surroundings are more likely to experience positive emotions and have better life satisfaction (Davidson, 2004). Being optimistic about the future can promote wellbeing and be protective for mental and physical health (Garrett et al., 2014)

It is acknowledged that research in this area is framed by the positivist paradigm, which suggests that one reality exists and endeavours to observe and measure information numerically. An alternative is the constructivist paradigm, which assumes that knowledge is socially constructed by people in the research process, and that research should attempt to understand the complexities of the lived experience from the point of view of those who live in it (Schwandt, 2000). Data is therefore rooted in context, and constructs such as wellbeing and self-esteem may not be measurable, or consistent across people. However, research available in the literature mainly comes from a positivist stance, which will be the framing for the current paper.

As follows from the wide definition of positive mental health, assessing the construct has been difficult. An example is Ryff (1989), who created a scale using six dimensions of positive mental health derived from the literature including self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. Other scales designed to measure positive mental health have focused on similar constructs, including optimism, life satisfaction, hopefulness, perceptions and judgements about sense of coherence and meaning in life, resilience, self-efficacy, social integration, and self-esteem (Barry, 2009).

The study of positive mental health has gained interest as indicators of positive mental health have been found to be associated with better physical health, fewer limitations in daily living, higher educational attainment, higher employment and earnings, better quality of life, better relationships and health behaviours (Boehm & Kubzansky, 2012; Ryff, 2014). Keyes (2005) categorised the general population in the United States into four categories: flourishing, moderately mentally healthy, languishing, and meeting criteria for diagnosable mental disorders. He found that adults who were moderately mentally healthy and those who were languishing showed more psychosocial impairment and poorer physical health, lower productivity, and more limitations to daily living compared to those who were flourishing. Longitudinal studies have also found that positive mental health is a protective factor against mental disorders at later time points (Grant, Guille, & Sen, 2013; Keyes, Dhingra, & Simoes, 2010; Lamers, Westerhof, Glas, & Bohlmeijer, 2015).

1.1 Self-esteem

One widely used indicator of positive mental health is self-esteem. Self-esteem is defined by the value people place on themselves, and is not determined by the accuracy of the evaluations (Baumeister, Campbell, Krueger, & Vohs, 2003; Greenwald et al., 2002; Rosenberg, 1965). High self-esteem can be an accurate and balanced appreciation of the person's worth and competencies, but can also refer to an inflated, unwarranted sense of superiority over other people. There is therefore argument in the literature that accurate views of the self, rather than inaccurate perceptions, are more useful, in the manner that accurate decision making should be guided by accurate information (e.g. Baumeister et al., 2003). However, most research available focuses on self-esteem as perception rather than reality, which will be the definition employed in this paper.

Several demographic variables have been identified to be associated with self-esteem. When examining self-esteem development in the general population, recent longitudinal studies suggest that age has an impact on self-esteem, with self-esteem increasing from adolescence to middle adulthood, peaking at around 60 years old (Orth, Robins, & Widaman, 2012). This increase in self-esteem is likely to be due in part to an increased sense of mastery and personal control as the individual ages (Wagner, Lüdtke, Jonkmann, & Trautwein, 2013). During young adulthood, individuals take on social roles (e.g. relationship partner, employee, parent) and these social roles involve social expectations about role-congruent behaviour. These social expectations translate into a development of mature personality traits, which are associated with higher self-esteem (Orth, Erol, & Luciano, 2018). In older age, evidence has been inconsistent. Some studies suggest that self-esteem remains relatively stable after age 60 (Wagner et al., 2013) whereas others show that self-esteem peaks between 60 to 70 years, then declines in old age, with a sharper decrease after 90 (Orth et al., 2018; Orth et al., 2012). This lack of consensus could be due to the moderating effect of factors such as variation in health, cognitive functioning, and socioeconomic status. For example, if an older adult is able to maintain their socioeconomic status and health, it is likely that self-esteem declines would be small. Further research will be needed into self-esteem in older age to account for these potential moderating effects.

In addition, men tend to report higher levels of self-esteem than women, and gender does not appear to affect the developmental trajectory of self-esteem, as detailed earlier (Orth et al., 2012; Wagner et al., 2013). Another important demographic variable is ethnicity. Some researchers have suggested that members of ethnic minorities show different patterns of self-esteem change as they age. For example, in a study with participants drawn from a national sample in the United States, Hispanics had lower self-esteem than African Americans and White Americans in adolescence. However, at age 30, African Americans and Hispanics experienced higher self-esteem than White Americans (Erol & Orth, 2011). While an increase in sense of mastery from adolescence to young adulthood accounted for a large proportion of the increase in self-esteem, ethnic differences, though small, remained significant after controlling for sense of mastery. Of note, there remains within group variability of self-esteem following experience of and reaction to discrimination among Black men in the US, pointing to possible difference between ethnic groups in terms of racial socialisation practices, and ways in which discrimination is perceived and evaluated (Mereish, N'Cho, Green, Jernigan, & Helms, 2016). Self-esteem was also found to have different correlates across 31 countries (Diener & Diener, 2009). Taken together, the literature suggests that different cultures may have different ways of construing the self, which may have consequences on the developmental trajectory of self-esteem.

Several findings have found that self-esteem has predictive effects for other areas of life. For example, self-esteem is positively related to increased effort and perseverance in the face of difficulties (Di Paula & Campbell, 2002). Self-esteem and mental wellbeing, as indicators of positive mental health, have been found to be associated with better physical health, higher educational attainment, higher rates of employment and earnings, better quality of life, better relationships and health behaviours (Friedli, 2009; NIMHE, 2005; Orth & Robins, 2022).

Evidence from Sowislo and Orth (2013)'s meta-analysis of longitudinal studies showed that there are significant cross-lagged effects, indicating that low self-esteem predicts later depression and anxiety. Trzesniewski et al. (2006) found that adolescents with low self-esteem tend to have poorer mental and physical health, lower economic wellbeing, and higher levels of criminal activity when they reach young adulthood. However, caution must be used in interpreting studies into self-esteem and its links to psychological outcomes due to methodological limitations of using subjective measurement methods and the potential of confounds. Nonetheless, self-esteem does appear to be linked to happiness and initiative, and weakly linked to academic and professional performance, social behaviours, addictions, and interpersonal relationships in another review of studies where authors emphasised inclusion of only studies with highly rigorous methods (Baumeister et al., 2003; Harris & Orth, 2020).

1.2 Intellectual Disability

Intellectual disability is defined by significant cognitive and functional deficits with onset during the developmental period, and is often associated with communication difficulties (Boat & Wu, 2015).

A recent systematic review of self-esteem of school aged youth with intellectual disabilities found a lack of relationship between age or sex and self-esteem (Maïano et al., 2019). Although the methodological quality of the reviewed studies was generally poor, and results have to be interpreted with caution, the findings appear to be in contrast with findings from typically developing youth, where there is consensus that self-esteem may decrease during the transition to adolescence (Harter, 1999), and that boys commonly show higher self-esteem than girls (Zimmerman, Copeland, Shope, & Dielman, 1997).

Few studies have investigated self-esteem in adults with intellectual disabilities. Of note is a study involving 128 adults with intellectual disability in Spain (Garaigordobil & Pérez, 2007) which found them to show lower self-esteem and more mental health symptoms than the general population. There were no gender differences in terms of self-esteem within the group with intellectual disabilities. One factor that could account for the lowered self-esteem and higher incidences of mental disorders is the experience of stigma (Matson, Anderson, & Bamburg, 2000).

Stigma has been conceptualised as the process of devaluation and marginalisation of certain groups, which reduces the person from a whole to a tainted and discounted one (Goffman, 2009). Many people with intellectual disabilities experience stigma, which may be explicit such as verbal abuse, or more implicit forms that restrict their abilities to lead a meaningful life, such as gaining employment (A. Jahoda & Markova, 2004). Negative attitudes, high levels of stigma, and denial of fundamental human rights persist in many parts of the world (Scior et al., 2020). The general public appears to have limited understanding of intellectual disability, with negative attitudes linked in part to misconceptions about what people with intellectual disabilities are capable of (Scior, 2011), and that they would need more protection, or that they should be avoided as they are dangerous (A. Jahoda, Wilson, Stalker, & Cairney, 2010).

A recent systematic review on how adults with intellectual disabilities construct their social identities found that most people seem aware of the intellectual disability label given to them, or view themselves as different from others (Logeswaran, Hollett, Zala, Richardson, & Scior, 2019). Most people feel negatively about the intellectual disability label and reported experiencing shame, discomfort, anger, powerlessness, and frustration. Some people reject the label as they see it to have little relevance and would prefer to focus their identity on other attributes or characteristics they have. Others may see the label as a threat and distance themselves from it (Logeswaran et al., 2019).

Given that most people are aware of the label, it is concerning that perception of stigmatisation has been associated with lower self-esteem and psychopathology in stigmatised groups, such as people with intellectual disabilities. For example, adolescents with intellectual disability who were most aware of being stigmatised had lowest self-esteem (Szivos, 1991). Among adults with intellectual disabilities, lower perceived stigma has been linked with higher self-esteem (Abraham, Gregory, Wolf, & Pemberton, 2002), and core negative beliefs about the self appear to be linked with experiences of feeling different in people with intellectual disabilities (Dagnan & Waring, 2004).

However, not all people who experience or are aware of stigma have low self-esteem. This suggests that some people do not internalise the messages and lessen the impact on how they view themselves. Instead of being put down by stigma, some people become angry because of the prejudice and unfair treatment, and this is considered a healthy response to discrimination (Corrigan & Watson, 2002). Rather than internalising others' stigmatising beliefs, resisting stigma has been associated with higher self-esteem, empowerment, and quality of life (Sibitz, Unger, Woppmann, Zidek, & Amering, 2009). Stigma resistance can include participation in self-advocacy groups, where members feel a sense of control and ownership and have possibilities to develop more positive identities such as being an expert and an independent person (S. Anderson & Bigby, 2017). People with intellectual disabilities can focus on other more positive attributes of themselves, including their roles and competencies (Logeswaran et al., 2019).

This suggests that people with intellectual disabilities may be able to reject the stigma, have a sense of control, and focus on more positive views of the self. The literature points to links between self-esteem and positive life outcomes, but little is known about predictors of self-esteem in adults with intellectual disabilities. Therefore, this study set out to address the following research questions:

1. What is the relationship between sociodemographic characteristics and self-esteem in individuals with intellectual disabilities?

2. Do wellbeing, sense of social power, self-efficacy in standing up to stigma, and negative reactions to discrimination predict self-esteem in individuals with intellectual disabilities? Wellbeing, sense of social power, and self-efficacy in standing up to stigma were hypothesised to be positively correlated with self-esteem.
3. What is the relative importance of the range of psychosocial variables in predicting self-esteem?

2. Methods

2.1 Joint Thesis Declaration

This was a joint project working in collaboration with fellow trainee, Maya Patel, who was examining the psychometric properties of the WEMWBS-ID for use with individuals with intellectual disabilities (Appendix J).

2.2 Design

This study used a non-experimental, correlational, cross-sectional design. Data collection was conducted online, and measures were administered through an individual interview using a video call with a researcher. Participants were asked to provide sociodemographic information and to respond to a range of scales measuring self-esteem, wellbeing, sense of social power, reactions to discrimination, and self-efficacy in responding to stigma. The relationship between these factors were considered, with a focus on how they might relate to self-esteem.

While Likert items may be ordinal, Likert scales, consisting of sums across several items, will be interval (Carifio & Perla, 2008). In addition, various studies have shown that the Pearson correlation and regression is robust with respect to skewness and non-normality (Havlicek & Peterson, 1976; Norman, 2010). To determine predictive relationship between sociodemographic characteristics and self-esteem, multiple regression was used. Associations between self-esteem and the psychosocial variables will be explored using Pearson correlation. The predictive relationship between self-esteem and the relative contributions of each psychosocial variable were examined with multiple regression.

2.3 Power analysis

As noted in the introduction, few studies have examined self-esteem within people with intellectual disabilities. Among the general population, self-esteem has been found to be associated with age, with an effect size of 0.32 from adolescence to young adulthood (Erol & Orth, 2011). Karatzias, Chouliara, Power, and Swanson (2006) found that self-esteem was strongly associated with wellbeing among adolescents. Paterson, McKenzie, and Lindsay (2012) found that among people with intellectual disabilities, self-esteem was associated with perceived stigma with an effect size of 0.41. With these studies as a guide, a power calculation was carried out using G*Power3 (Faul, Erdfelder, Lang, & Buchner, 2007), assuming a medium effect in a multiple regression analysis with 10 predictors, with alpha = 5%, and desired power = 80%. The required sample was estimated at 95.

2.4 Self-advocate advisors

Self-advocate advisors were part of the larger research study regarding an intervention focusing on people with intellectual disabilities' capacity to resist stigma (STORM). They advised on the recruitment processes, measures, and procedures for their administration. They were recompensed for their input and were represented on the STORM Study Management Group.

2.5 Measures

The measures used were reviewed by self-advocate advisors with intellectual disabilities in order to ensure that the questions were readable and understandable. As feedback from self-advocates suggested that they struggled with the option 'rarely' used in the original Warwick-Edinburgh Mental Wellbeing Scale (Tennant et al., 2007), all our measures were administered using a four-point scale, ranging from “never”, “sometimes”, “often”, to “always”. Response scales were presented with blocks of increasing size to act as visual cues alongside the written response categories. The measures were successfully used in a pilot study completed by the larger research team.

2.5.1 Adapted Rosenberg Self-esteem Scale (RSES)

The six-item version of the Rosenberg Self-esteem Scale, adapted for people with intellectual disabilities (Dagnan & Sandhu, 1999), was used to measure global self-esteem in adults with intellectual disabilities. They used a five-point Likert scale response, and reported a Cronbach’s α of 0.62 and test-retest reliability of 0.68 (Dagnan & Sandhu, 1999). The total score is calculated by reverse scoring the negatively worded items and summing the total. In our study, the total score ranged from 4 to 24, where higher scores reflected higher self-esteem (Appendix D).

2.5.2 Warwick-Edinburgh Mental Wellbeing Scale-ID (WEMWBS-ID)

The 14-item Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) measures wellbeing focusing on positive aspects of mental health (Tennant et al., 2007). In a student sample and a sample representative of the UK population, the scale showed a Cronbach’s α score of 0.89 to 0.91, with high test-retest reliability of 0.83 (Tennant et al., 2007).

Members of the research team have adapted the WEMWBS for use with individuals with intellectual disabilities (WEMWBS-ID), including changing the wording of some items (e.g. “I’ve been feeling optimistic about the future” was reworded to “I felt hopeful about the future”), shortening the 2-week reference window to 1 week, and reducing the original 5-point to the same 4-point scale as used for the other measures. The total score ranged from 14 to 56, where higher scores reflecting better mental wellbeing (Appendix E).

The psychometric properties of the WEMWBS-ID for use with individuals with ID have yet to be examined. This was the aim of Maya Patel’s research.

2.5.3 Sense of Power Scale

C. Anderson, John, and Keltner (2012) defined personal sense of power as the perception of one's ability to influence another person or other people. They developed an eight-item scale with seven response categories measuring individuals' sense of power within various social contexts. They found that when examining social power at the generalised level, the scale has a Cronbach's α of 0.82 to 0.85, indicating internally consistent and coherent power-related beliefs even when no specific context was specified.

In our study, we retained four items in the scale, with the language simplified whilst keeping the original meaning. The items used in this study were: 'I can get other people to listen to me', 'I can get others to do what I want', 'I get to make decisions', 'Others pay attention to my views'. This scale showed acceptable internal consistency with a Cronbach's α of 0.67 in an unpublished pilot study conducted by the research team (Scior et al., 2020). Scores ranged from 4 to 16, where a higher score indicating more perceived social power (Appendix F).

2.5.4 Negative Reactions to Discrimination

Ali, Strydom, Hassiotis, Williams, and King (2008) developed a ten-item self-report instrument measuring perceived stigma in people with ID. Two underlying factors described dimensions of stigma. The "perceived discrimination" subscale described reactions of others to people with intellectual disabilities, while the "reaction to discrimination" subscale examines the emotional reactions of the people confronted with stigma. From the perspective of the stigmatised, there may be emotions of shame, embarrassment, alienation, fear and anger, of which shame can be a particularly distressing feature of stigma. According to Ali et al. (2008), the Cronbach's α for the four-item (negative) reactions to discrimination subscale was 0.69. This was the subscale that was used in our study. Scores ranged from 4 to 16, where a higher score indicated more negative emotional reactions to stigma (Appendix G).

2.5.5 Self-efficacy in Rejecting Prejudice (SERP)

This is a single self-rated item: “At this moment, how confident do you feel about standing up to prejudice?”. Higher scores indicate more confidence in rejecting prejudice (Appendix H).

2.5.6 Psychometric properties of the measures used

The internal consistencies of the measures used in this study were calculated. Good internal consistency was found for the WEMWBS ($\alpha = 0.86$), and fair for the adapted RSES ($\alpha = 0.70$). The other scales have yet to be validated and would be the focus of further research. As a minimum, internal consistencies were calculated. Cronbach’s α for the Sense of Social Power scale was 0.57, but improved to 0.63 if the third item was removed. All subsequent analyses were therefore run without the third item. The Negative Reactions to Discrimination scale showed fair internal consistency ($\alpha = 0.63$).

2.6 Participants

The study involved 96 participants with mild to moderate intellectual disabilities of whom 44 were participants recruited for the purposes of this study and the examination of the psychometric properties of the WEMWBS-ID, 22 were baseline data from participants involved in STORM, and 30 were recruited for the purposes of a previous research project aimed to develop a tool to assess response to stigma.

The inclusion criteria were as follows: 1) aged 16 years and above; 2) have intellectual disability as defined by an administrative definition, in terms of receipt of specialist services for people with intellectual disabilities within the education, social care, third or health sector; 3) have sufficient expressive and receptive communication skills in English to be able to complete measures with support; 4) have capacity to provide informed consent to participate in the study.

2.7 Procedure

All participants from STORM, the previous research project, and the current pool were recruited following the same recruitment process.

Participants were recruited via Mencap's national network, advertisements circulated through social media channels and third sector organisations throughout the UK (Appendix A). In addition, 76 organisations that worked with adults with intellectual disabilities were identified through internet searches and contacted via email. An Easy Read Information Sheet was provided to organisations and individuals (Appendix B). The majority of contact was through staff who supported people with intellectual disabilities, who helped share information of the study. Where individuals or groups expressed interest, the researcher met with them together with a familiar member of staff virtually to explain the project and answer questions. If they expressed interest in taking part, further individual video calls were organised to obtain informed consent and carry out data collection. (See Appendix C for the consent form). All measures were administered through a video call, with the measures in Qualtrics shared on the screen. Items were read aloud by the researcher, and responses were recorded by the researcher. Researchers debriefed participants, checked if they were distressed by completing the questionnaires, and provided support as needed.

Sociodemographic information was collected first. Participants then completed two practice questions to orientate to the Likert scale, which was presented with a visual aid depicting the difference between response options (never, sometimes, often, always). If participants understood the questions and response scale, the formal questionnaires were administered (Appendix D – H). Participants could take a break and were reminded they could stop at any time. Upon completion, a £10 voucher for a retailer of their choice was emailed to them to thank them for their time.

2.8 Ethical Considerations

Ethical approval was in place as part of the STORM study. An amendment was made to allow for recruitment of participants outside of the original STORM intervention. See Appendix I for ethics amendment and approval from the UCL ethics committee.

Concerns about secondary use of data revolve around confidentiality and the issue of return for consent. Identifying information were removed from the data collected in the previous studies. The aims of the current research were broadly in line with the participants original consent in finding out how people with intellectual disabilities think about themselves and their place in the world.

The other main ethical considerations were around capacity to consent and the risk of participants experiencing distress in response to some of the questions. Information sheets were developed with close input from people with intellectual disabilities and were available in Easy Read format. Time was given for participants to ask questions and help them understand the advantages and disadvantages of taking part. Participants were given at least 24 hours to consider and discuss with trusted others if they wished to.

In order to ensure that the risk of any discomfort or distress arising from any of the questions was managed, rapport was built during the recruitment process, trusted people were identified so that the participant could be directed to them if needed, and the researchers offered a debrief at the end of each data collection session to ensure participants' wellbeing. Participants were reminded they could take a break or stop the session at any time. In the event, no participant showed any sign of undue distress.

3. Results

3.1 Sample Characteristics

Participants were aged between 18 to 74 years (M = 38.8, SD = 12.2). Other sociodemographic characteristics are presented in Table 1.

Table 1

Sociodemographic Characteristics of Participants

Sociodemographic characteristics	n	%
Gender		
Male	51	53.1
Female	45	46.9
Ethnicity		
White British/White Other	81	84.4
Asian British/Asian Other	6	6.3
Black British/African/Caribbean/Black Other	5	5.2
Other	4	4.2
School		
Mainstream	31	32.3
Special needs	45	46.9
Both	16	16.7
Unsure	4	4.2
Living situation		
On their own	25	26.0
With parent or family member	35	36.5
With partner	8	8.3
In supported living	23	24.0
Other	5	5.2
Self-advocacy groups		
Yes	67	69.8
No	26	27.1
Unsure	3	3.1

Demographic data was extracted to compare our sample to the UK population. There is limited evidence to suggest that prevalence rates of intellectual disabilities among minority ethnic groups are similar to or greater than prevalence rates among majority ethnic groups, although these findings might be impacted by methodological constraints in diagnosing intellectual disabilities in the different groups (Hatton, 2002). According to the 2011 Census of the general UK population, 86.0% of the population was White, 7.5% were from Asian ethnic groups, 3.3% were from Black ethnic groups, and 3.2% were from Mixed/Other ethnic groups. Broadly, our sample appears to be representative of the UK population.

3.2 Self-esteem, Wellbeing, Sense of Power, Negative Reactions to Discrimination, Self-efficacy in Rejecting Prejudice Scores

The mean score for self-esteem (adapted RSES) was 18.67 (*SD* = 3.42) where higher scores represent higher self-esteem (possible maximum of 24). The mean wellbeing score (WEMWBS-ID) was 41.39 (*SD* = 7.66), where a higher score represents better mental wellbeing (possible maximum of 56). The mean sense of power score was 8.11 (*SD* = 2.22) out of a possible maximum of 12. The mean score on the Negative Reactions to Discrimination scale was 8.52 (*SD* = 2.56) out of a possible maximum of 16, suggesting less negative emotional reactions to stigma. The mean response on the SERP was between "sometimes" and "often" (*M* = 2.71, *SD* = 1.07), suggesting some confidence in rejecting prejudice.

3.3 Sociodemographic characteristics as predictors of self-esteem

A multiple linear regression analysis was carried out to investigate if sociodemographic characteristics significantly predicted self-esteem. Scatterplots were used to visually inspect the data and rule out possible non-linear relationships (Figure 1). Dummy variables were created to code for categorical variables. An analysis of standard residuals was carried out, which showed that the data contained no outliers (Std. Residual Min = -2.29, Std. Residual Max = 2.02). Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern. The model met the assumption of independent errors (Durbin-Watson value = 2.12). The histogram of standardised residuals indicated that the data contained approximately normally distributed errors, as did the normal P-P plot of standardised residuals, which showed points that were not completely on the line, but close. The scatterplot of standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

The results of the regression indicated the model was not statistically significant. Sociodemographic characteristics explained 12.6% of the variance ($R^2 = .126$, $F(14, 80) = .826$, $p = .640$). None of the sociodemographic predictors emerged as significant.

Figure 1

Scatterplots of Self-esteem on various Sociodemographic Characteristics

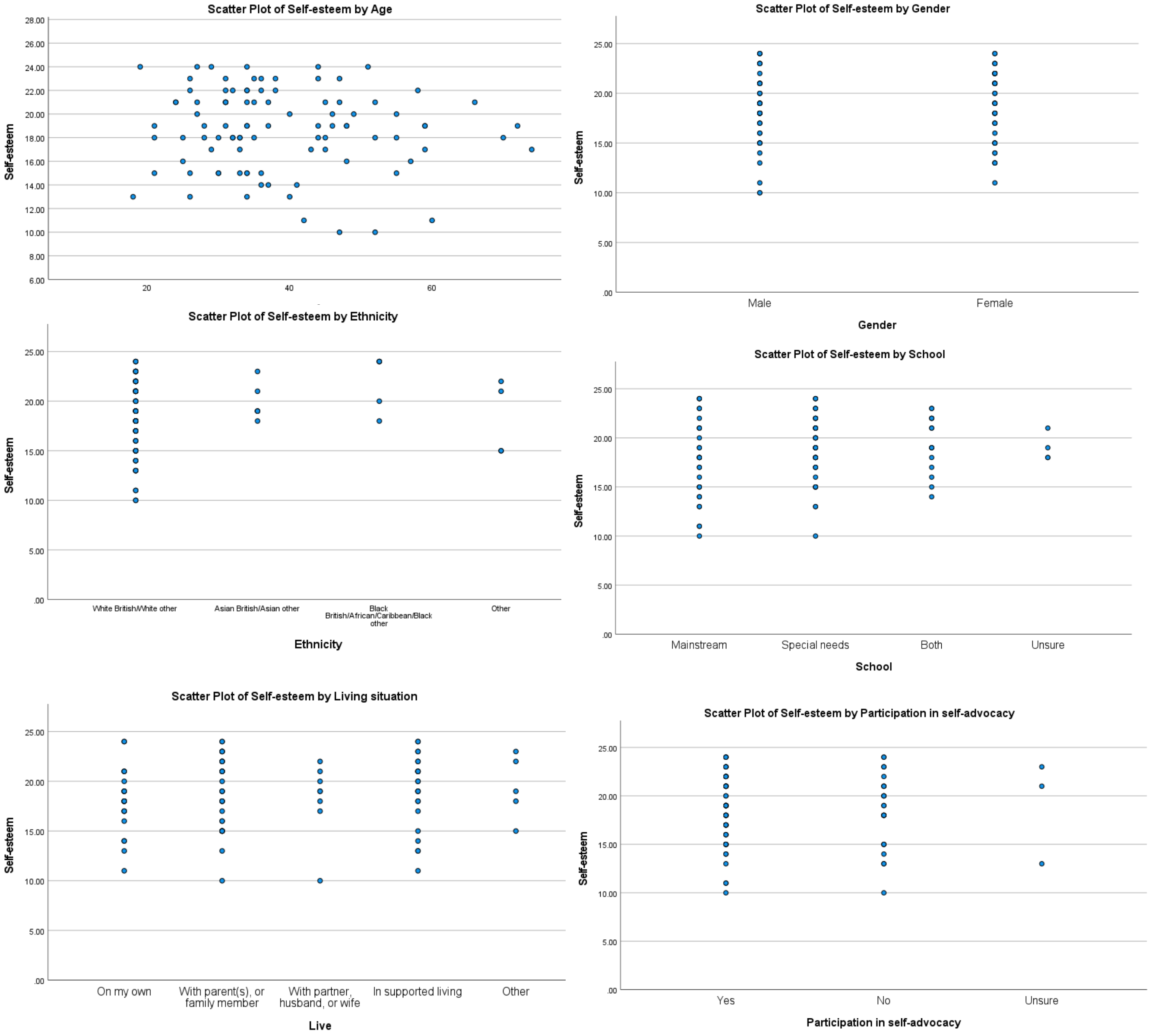

Table 2

Summary of Regression Analysis for Sociodemographic Characteristics predicting Self-esteem

Sociodemographic Characteristics	*B*	*SE B*	*β*	*p*
Age	-0.025	.038	-.090	.510
Gender (Male)	-0.108	.755	-.016	.887
Ethnicity				
White British/White Other	-0.685	1.95	-.073	-.351
Asian British/Asian Other	0.774	2.43	.055	.751
Black British/African/Caribbean/Black Other	3.02	2.49	.197	.229
School				
Mainstream	-0.951	2.04	-.131	.642
Special Needs	0.673	1.98	.099	.735
Both	1.01	2.15	.111	.639
Living Situation				
On own	-0.995	1.87	-.128	.597
With parent(s), or family member	-1.21	1.89	-.171	.524
With partner	-1.00	2.22	-.081	.654
In supported living	-0.451	1.94	-.057	.816
Self-advocacy groups				
Yes	-0.909	2.34	-.123	.699
No	-1.16	2.36	-.152	.624

Note: Gender, ethnicity, schooling, living situation, attendance in self-advocacy groups were represented as dummy variables.

3.4 Relationship between Self-esteem, Wellbeing, Sense of Social Power, and Self-efficacy in Rejecting Prejudice

Figure 1 shows the scatterplot for self-esteem on wellbeing, sense of social power, negative reactions to discrimination, and self-efficacy in rejecting prejudice. On visual inspection, a linear relationship between the variables was deemed appropriate. Table 3 displays the correlations from a Pearson's correlation analysis between self-esteem, wellbeing, sense of social power, negative reactions to discrimination, and self-efficacy in standing up to stigma. Higher levels of self-esteem were associated with higher levels of wellbeing ($r = .649$, $p < .001$), higher sense of social power ($r = .297$, $p = .017$), and higher sense of self-efficacy in rejecting prejudice ($r = .426$, $p < .001$). Higher levels of wellbeing were associated with higher sense of social power ($r = .492$, $p < .001$).

Figure 2

Scatterplots of Self-esteem on wellbeing, sense of social power, negative reactions to discrimination, and self-efficacy in rejecting prejudice

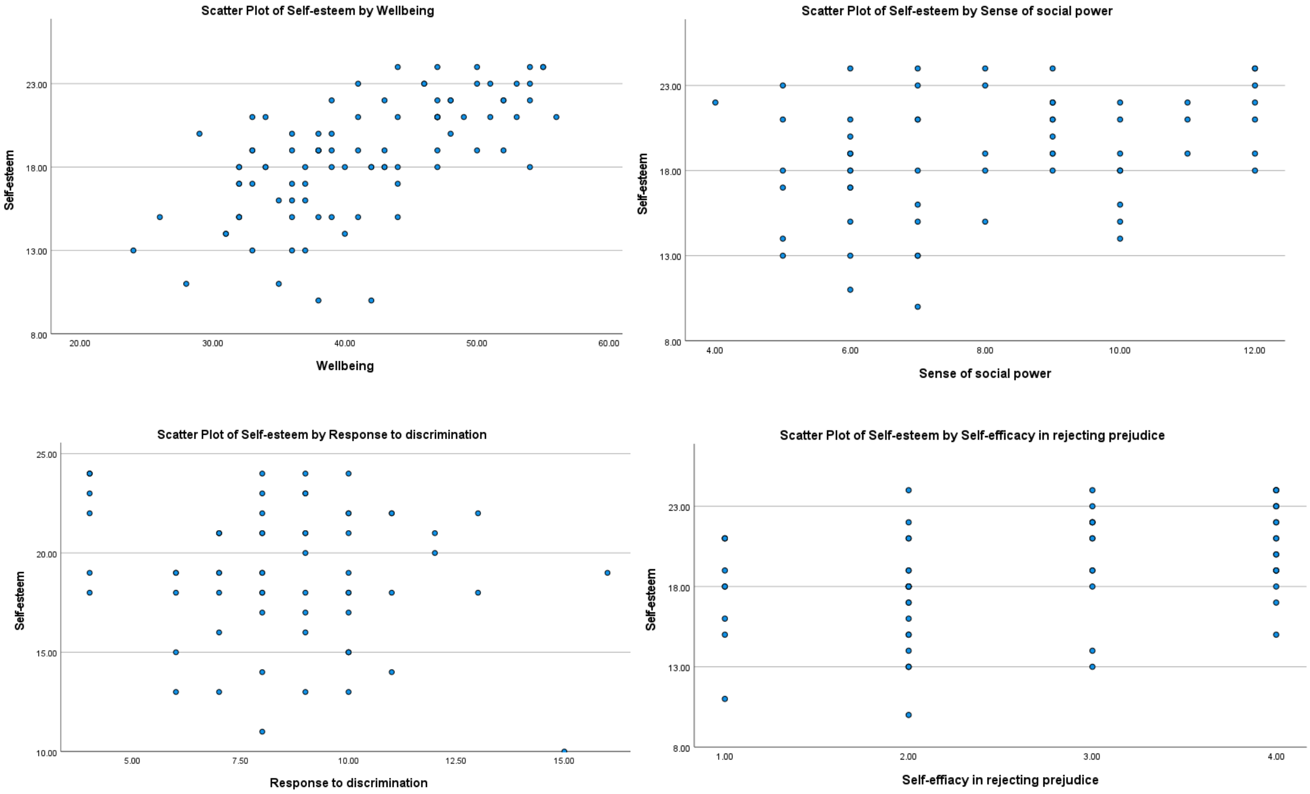

Table 3

Pearson's correlation between measures of self-esteem, wellbeing, sense of social power, negative reactions to discrimination, and self-efficacy in rejecting prejudice

Measure	1	2	3	4	5
1. Self-esteem	-				
2. Wellbeing	.649**	-			
3. Sense of social power	.297*	.492**	-		
4. Negative reactions to discrimination	-.197	-.032	.178	-	
5. Self-efficacy in rejecting prejudice	.426**	.234	.132	-.097	-

Note. ***p* < .01, **p*<.05

3.5 Predictors of Self-esteem

A multiple linear regression was run to determine the relevant contribution of wellbeing, sense of power, negative reactions to discrimination, and self-efficacy in rejecting prejudice for predicting self-esteem. Although correlation with self-esteem was found to be insignificant, negative reactions to discrimination was added to the model in order to answer the initial research question about the relative importance of these constructs in relation to self-esteem. It was deemed important to control for the interrelationships of all the predictors, and insignificant coefficient estimates also provide information about what variables are not effective at explaining changes in the outcome variable (Heinze & Dunkler, 2016). As none of the sociodemographic characteristics were significant predictors of self-esteem, they did not need to be controlled for and were not added into the current model.

An analysis of standard residuals was carried out, which showed that the data contained no outliers (Std. Residual Min = -2.82, Std. Residual Max = 2.29). Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern (Wellbeing, Tolerance = .718, VIF = 1.39; Sense of social power, Tolerance = .719, VIF = 1.39; Negative reactions to discrimination, Tolerance = .940, VIF = 1.06; SERP, Tolerance = .935, VIF = 1.07). The model met the assumption of independent errors (Durbin-Watson value = 2.48). The histogram of standardised residuals indicated that the data contained approximately normally distributed errors, as did the normal P-P plot of standardised residuals, which showed points that were not completely on the line but close. The scatterplot of standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

Wellbeing, sense of power, negative reactions to discrimination, and self-efficacy in standing up to prejudice explained a significant amount of the variance in self-esteem, $R^2 = .524$, $F(4,59) = 16.2$, $p<.001$. Wellbeing and self-efficacy in rejecting prejudice significantly predicted self-esteem. See Table 4 for summary of regression analysis.

Table 4

Summary of Regression Analysis for Variables predicting Self-esteem

Variable	*B*	*SE B*	*β*	*p*
Wellbeing	0.258	.047	.578	<.001
Sense of power	0.005	.163	.003	.978
Negative reaction to discrimination	-0.204	.124	-.152	.106
Self-efficacy in rejecting prejudice	0.879	.296	.275	.004

4. Discussion

The overall aim of this study was to explore to what extent sociodemographic characteristics, wellbeing, sense of social power, negative reactions to discrimination, and self-efficacy in standing up to stigma may predict self-esteem in adults with intellectual disabilities. No association between sociodemographic characteristics and self-esteem was observed. Higher self-esteem was associated with higher levels of wellbeing, sense of social power, and self-efficacy in rejecting prejudice. When considered together, wellbeing and self-efficacy in rejecting prejudice were significant predictors of self-esteem, jointly accounting for 52.4% of the variance in self-esteem.

4.1 Relationships between sociodemographic characteristics and self-esteem

The lack of an association between sociodemographic characteristics and self-esteem in the present study stands in contrast with evidence from the general population, which suggests that self-esteem tends to be higher in men, increases with age and remains stable or decreases after the age of 60 (Orth et al., 2012; Wagner et al., 2013). Research with the general population has found that self-esteem appears to have a stable, trait-like core, as well as a state-like, time-varying factor (Alessandri, Vecchione, Donnellan, & Tisak, 2013). Into adulthood, self-esteem increases and becomes more stable, which could represent the stabilisation of life conditions (Wagner et al., 2013; Wagner, Lüdtke, & Trautwein, 2016).

One possible explanation for the divergence of findings from this picture with the present sample of adults with intellectual disabilities is that while members of the general population may take on more socially valued roles as they age, such opportunities may be very much reduced for adults with intellectual disabilities. Continuing education, employment, development of intimate relationships, construction of a family unit are potential areas that adults with intellectual disabilities struggle to access. According to Crawford (2013), in a study of more than 53,000 people with intellectual disabilities in Canada, 50.6% of participants with intellectual disabilities stated that they had experienced discrimination in the workplace, 19.5%

felt they were trusted with fewer responsibilities than other employees, and 19.5% reported that they had been paid less for the same work than employees without intellectual disabilities. In England, NHS Digital (2021) reported only 5.1% of working age adults with intellectual disabilities known to their local authority were in paid employment. Being hindered from participating in socially valued roles could mean that people with intellectual disabilities do not experience an increase in feelings of competence and a sense of mastery in the same way as members of the general population may. For the general population, having control over one's life is seen to be an important indicator of relational value and consequently influences self-esteem (Wagner et al., 2013). Of note, in the longitudinal Whitehall II study of 10,314 British civil servants, they found that low social support at work was related to poor mental health, poor health functioning, and increased sickness absence (Marmot et al., 1991). The difference in life experiences in people with intellectual disabilities could explain for the lack of association between age and self-esteem.

The lack of significant association between self-esteem and ethnicity was surprising, particularly given the context of how cultural norms, socialisation, and social support might be different across cultures (Mereish et al., 2016). Literature suggests that different cultures may have different ways of construing the self (Diener & Diener, 2009). In our study, it is likely that we did not find any significant associations between self-esteem and ethnicity due to the small numbers of participants in the Asian/Black/other ethnic groups. While our sample appears to be representative of the UK population in terms of ethnic makeup, the small cell sizes in this analysis would have made statistical comparisons lack power. A larger scale study would be warranted.

Interestingly, no associations between type of school attended or living situation and self-esteem were found. This could reflect how results are mixed in the wider literature. Higher independence in living environment was linked with higher self-esteem (Griffin, Rosenberg, Cheyney, & Greenberg, 1996), though other studies have found that there were no differences in self-esteem between people living in the community and those living in institutions with less independence (Barlow & Kirby, 1991).

4.2 Wellbeing, sense of social power, self-efficacy in standing up to stigma, and negative reactions to discrimination

The hypothesis that increased wellbeing, sense of social power, and self-efficacy in standing up to stigma would be associated with higher self-esteem was confirmed. Relevant to this finding is literature around how people with intellectual disabilities resist stigma they face. Many people with intellectual disabilities, based on their previous negative experiences, expect people to treat them unfairly (Logeswaran et al., 2019). Stigmatised individuals may respond through self-stigmatisation, avoidance, self-restoration, or by resisting stigma through challenging and deflection (Thoits, 2011). Challenging is defined by pushing back against the stigma, while deflection hardens the individual against stigma to minimise the negative psychological effects. In agreement with this theory, Firmin et al. (2017) developed a framework of stigma resistance that involves personally vocalising beliefs in line with stigma resistance (such as having equal rights), developing personal empowerment through learning, such as learning about the effects of stigma, and finally educating and challenging stigma in the public level. People with intellectual disabilities who feel able to resist the stigma and prejudice they may face could have better wellbeing and self-esteem in that they do not agree with negative stereotypes, thus preserving the self (Corrigan & Rao, 2012).

Nonetheless, the current research is cross-sectional and directionality of links between these concepts remains to be investigated. It is unclear if the positive experience of being able to exert social power and having a clear role in representing one’s views, such as in self-advocacy groups, could be linked with developing a more positive self-identity and more positive self-esteem. Conversely, those with higher self-esteem might be more resilient to negative experiences and feel more able to stand up for themselves and exert social power.

4.3 Relative importance of psychosocial variables in predicting self-esteem

When variables were considered together in the model, only wellbeing and self-efficacy in rejecting prejudice were significant predictors of self-esteem, with wellbeing as the strongest predictor of self-esteem. This finding is in line with the literature on self-esteem in the general population. Several studies have shown that subjective wellbeing significantly correlates with higher self-esteem (Mann, Hosman, Schaalma, & de Vries, 2004). Notably, in a large scale study of more than 13.000 participants across 31 nations, correlations between self-esteem and wellbeing were found across the samples and in most nations, though the size of the correlations differed cross-nationally (Diener & Diener, 2009).

It is important to establish that while closely related, self-esteem and wellbeing appear to be separate concepts. Self-esteem can be thought of as a judgement of oneself, whereas wellbeing is more a subjective judgement of one's life circumstances, either in terms of cognitive evaluations or ongoing emotional affect. For example, in the measurement of self-esteem in this study, the adapted RSES involved questions such as whether the person feels they are as good or able to do things as well as other people. On the other hand, when examining wellbeing, the WEMWBS-ID looks into the overall affect (e.g. "I felt relaxed") and evaluations of life (e.g. "I dealt with problems well", "I thought clearly", "I felt close to other people"). In the wider literature, self-esteem and wellbeing have different patterns of relationships with other variables (e.g. gender). In particular, financial satisfaction related to wellbeing beyond the influence of self-esteem (Diener & Diener, 2009). This suggests that while wellbeing is likely to influence self-esteem and vice versa, they are discriminable constructs.

4.4 Impact of the Covid-19 pandemic and associated restrictions

This research was undertaken in the context of the Covid-19 pandemic. The impact of a nationwide UK lockdown, closure of day centres and interruption of group meetings and activities means that people with intellectual disabilities likely had less social contact with others, thus impacting on their wellbeing and self-esteem. In the UK covid-LD study, only 47%

of people with mild to moderate intellectual disabilities felt they were getting the same support as they were before the pandemic, and 41% reported that they were going out less than they were before the pandemic (Flynn et al., 2021). Broadly however, in our study, it appeared that participants' self-esteem was generally at the higher end of the scale. One explanation is that participants were recruited through charities and groups. In this manner, participants were generally linked in with their community and more likely to be engaged in activities such as self-advocacy. Despite social restrictions associated with the pandemic, many groups were able to adapt and continue to keep in contact with their members. This is in contrast with the larger UK statistic, that only 53% of people with intellectual disabilities continued to take part in online activities (Flynn et al., 2021). This could mean that our sample may not be representative of people with mild to moderate intellectual disabilities, many of whom may have been much more isolated during the pandemic than the present sample. As such, the present findings may paint an overly optimistic picture of self-esteem in adults with intellectual disabilities, something that should be followed up in further research.

Another possibility is that the pandemic may have provided something of a leveller. With the pandemic and social restrictions affecting everyone, adults with intellectual disabilities for once had similar experiences as members of the general population. This would be in contrast to the stigma and differential opportunities they had experienced in the past. Perhaps this more "level playing field" led adults with intellectual disabilities in the current study to feel better about their situation and themselves.

4.5 Limitations

In terms of participants and recruitment, the sample was self-selecting. People who feel less well about themselves or are more anxious or socially isolated are likely to have been less aware of the study and/or less interested in taking part. Data were collected with the researcher reading the questions and asking participants for responses. Our results could be subject to response bias and social desirability factors, therefore artificially inflating self-esteem scores.

While great care was taken to ensure that participants knew there was no right or wrong answer, we are unable to ascertain if scores would be different if participants completed the measures on their own. Nonetheless, this would have led to further complications of ensuring that participants were able to fully understand the questions and complete them independently.

Another possibility would be that given the context of lockdown, the experience of meeting a new person was rare and was interpreted as a positive event to look forward to. The positive emotions experienced could have in part brought about more hopeful answers in the measures completed. This is confirmed by the very positive responses of participants in the STORM study, where qualitative feedback from participants was collected as part of the feasibility study, which provided part of the present sample. Participants' narrative accounts of completing the measures online were overall very positive, for example feedback included "I really liked when it was just me and [researcher name], meet up and doing questionnaires on Wednesday" (Scior et al., 2022).

In terms of the study design, it has to be emphasised that this was a cross-sectional, correlational study. While we can identify associations between the factors studied, the directionality of the effects needs to be studied further. There is a likelihood of reciprocal effects, creating a positive feedback loop between self-esteem, wellbeing, and self-efficacy in rejecting prejudice. This would be in line with the literature of personality development, that personality characteristics and life experiences influence each other reciprocally (Nye & Roberts, 2019).

In addition, there have been disagreements in the literature about the factor structure of the RSES. Researchers have argued that there are multiple substantive dimensions in the scale, and that the single-factor model used as the basis of research with the RSES is inappropriate when used with the general adolescent population (Marsh, Scalas, & Nagengast, 2010; McKay, Boduszek, & Harvey, 2014). However, in a recent large-scale study of college students, different structural models for the RSES were evaluated (Donnellan, Ackerman, & Brecheen, 2016). While a unidimensional model fit the observed data less than models which accounted for correlations between positively and negatively keyed items, it was concluded that there was no compelling evidence that different structural models had substantive implications on common wellbeing and personality factors (Donnellan et al., 2016). When studied with the intellectual disability population, factor analytic methods showed a two factor structure and two specific items failing to factor (Davis, Kellett, & Beail, 2009). One of these items was included in the Dagnan and Sandhu (1999)'s adaptation of the RSES, which was the version used in this current study. Further research into the validity and reliability of the scale should be considered.

Finally, the reliability of the measures used was generally low. In particular, the measure of self-efficacy in rejecting prejudice was a single-item measure. The validity and reliability of the measure has yet to be established. This reflects the need for the field to continue to develop and validate measures that could be used with this population. While there are arguments that scores from Likert items are ordinal and intervals between positions on the scale are not numerically uniform increments, others have argued that Likert scales can be treated as interval and the correlations and regressions are robust to handle these data (Havlicek & Peterson, 1976; Norman, 2010), which is the stance taken in this study.

In addition, rather than relying on how people feel they might respond (e.g. self-efficacy in rejecting prejudice), it may be more useful to look at their abilities and how they might respond, such as capturing how people with intellectual disabilities respond to prejudice, through the Responding to Intellectual Disability Stigma Tool (Goldsmith-Sumner, 2021).

4.6 Implications

Although the current research is limited in allowing conclusions about causality, it does point to the possibility of leverage points available to clinicians to promote positive self-esteem in adults with intellectual disabilities. It is worth supporting adults with intellectual disability to engage in stigma resistance, and it is hoped that with increased confidence in rejecting prejudice, we might see knock on effects in terms of increased self-esteem. This can be done not only in the individual therapy room, but within the wider societal context. Clinicians can do much to encourage and empower people with intellectual disabilities to stand and advocate for themselves, such as by supporting people to do consultative roles in public policy planning, engage in media, and campaign for their rights.

Importantly, we note that not all people with intellectual disabilities have low self-esteem. While professionals need to acknowledge the limitations and unequal access to opportunities people with intellectual disabilities experience, there is a need to understand how they see themselves without making assumptions. Focusing on their strengths and positives can allow people with intellectual disabilities to feel better about themselves and empower them, rather than reinforce stigmatising narratives.

4.7 Future research

Given the particular context of Covid-19, it would be interesting to track if there are changes in self-esteem as societies return to a more normal life. It is entirely unclear if a ‘new normality’ may allow people with intellectual disabilities to engage in more meaningful lives and socially valued roles, thus having more positive experiences that could relate to their self-esteem, or if a return to the status quo might spell more negative consequences.

It would be worth further investigating the nature of the relationships between self-esteem, wellbeing and self-efficacy in rejecting prejudice. It would be interesting to carry out longitudinal studies to track the developmental trajectory of these factors, and to examine how they might interact with each other and also with sociodemographic characteristics over time. Finally, intervention studies would help to shed light on the causal links. Recent methodological developments in the casual inference literature have shown that the causal effect of non-randomised interventions can be reliably estimated. It is of priority to find ways to support this stigmatised population in resisting the stigma, such as through the STORM project, and any gains in self-esteem would not only help the individual but also shed light to the nature of the relationships between stigma resistance and self-esteem.

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Part 3: Critical appraisal

1. Introduction

This critical appraisal aims to explore the process and challenges of undertaking research on the self-esteem of individuals with intellectual disabilities, in the context of the Covid-19 pandemic. First, it will begin with the rationale and motivations of this research, learnings from joint working with a fellow trainee, the process of recruitment and online data collection, as well as a discussion on the concept of self-esteem.

2. Rationale

Pre-training, I worked with children with specific learning difficulties and their families. I saw how children with specific learning difficulties, in particular dyslexia, struggle academically and also socially, as many experienced bullying and teasing by peers. This experience appears to be in line with the wider literature on children with learning difficulties, particularly children with dyslexia, tended to have low self-esteem, felt isolated in schools and that up to half were regularly bullied (Glazzard, 2010; Humphrey, 2003; Humphrey & Mullins, 2002). In response, we conducted outreach workshops to educate teachers and parents about the condition, and also held courses such as speech and drama to help build our children's confidence in themselves. We had anecdotal feedback that these efforts have helped build our students' self-esteem, and allowed them to be more confident in themselves. Several of our children were able to advocate for themselves in school. When the opportunity came to look into the experiences of individuals with intellectual disabilities, I became interested to find out if people with intellectual disabilities would have similar experiences to the children I worked with.

However, I was surprised to find that there were few empirical studies or reviews looking specifically into the self-esteem of individuals with intellectual disabilities. Those that did tended to focus on children (Maïano et al., 2019). This was a sentiment I identified with – that children and young people seem to garner more interest and potentially have access to more services, but there seems to be less interest and provision available in adulthood. Sadly, this contrast between the fairly comprehensive school-age services and limited adult supports was echoed in a published review of services in Singapore (Poon, 2015). This prompted the systematic review into what is known about self-esteem in adults with intellectual disabilities, and the enquiry into the predictors for self-esteem.

3. Joint Project

The study was a joint project with a fellow trainee. I am thankful that we had a good working relationship and friendship, and were able to support each other as we undertook tasks outside of our usual expertise (e.g. creating advertisement posters, engaging in social media). We were able to bring different perspectives and ideas, discuss dilemmas and questions, and problem solve difficulties along the way, both for the systematic review and the empirical study. For example, when completing the systematic review, introducing the quality assessment I used to her and discussing and resolving any discrepancies helped me develop a clearer understanding of the tools I was using. Through discussion, I was able to form clearer arguments in my mind about the decisions I made.

In addition, I am grateful for how she helped to motivate me and keep me on track. The emotional and peer support she provided helped me to manage my anxiety and stress throughout the process. In this manner, I identified with the research from Jones and Thompson (2017) about the contributing factors to resilience among trainee clinical psychologists, particularly in this case, social support. Being able to empathise with someone else in the same boat and to elicit encouragement and support from someone else helped me to cope with the stress faced.

Furthermore, it was useful to receive support from someone who was also involved in the data collection process, to help ensure that we were both not pulled into interacting with our participants as if they were our clinical patients (Hay-Smith, Brown, Anderson, & Treharne, 2016). This was particularly important to me as I was starting placement in a specialist mental health service for people with intellectual disabilities towards the start of the data collection phase, and was finding it hard to manage the boundaries between clinician and researcher. Conversations with a fellow researcher helped me to reflect on the role and scope of being a researcher, especially when participants disclose difficult past experiences.

4. Recruitment

Participants were recruited by contacting organisations that supported people with intellectual disabilities and by sharing the recruitment advertisement on social media platforms. It was encouraging to be able to see the reach of our research across the nation, managing to get interest from groups across the UK.

Recommendations have been made in the literature in terms of recruitment to intellectual disability research, in response to common difficulties faced by people with intellectual disabilities in participating in research, including interview anxiety, difficulties in understanding the concept of research, and worry about negative feedback (Nicholson, Colyer, & Cooper, 2013). The research team is recommended to take a personal approach, arrange multiple formal and informal meetings with potential participants so they are familiar with the study aims and research team, ensure flexibility around the recruitment process, ensure that the interview is as enjoyable as possible, and to involve carers and staff throughout the process (Lennox et al., 2005; Nicholson et al., 2013). These factors were present in this study, such as by having online correspondence with staff to introduce our project and establish the potential impact of our project, then organising informal meetings to introduce the researchers and the project to the potential participants, and to answer any questions they might have. Meetings were arranged at flexible timings, such as when group members regularly met, or around potential participants' work schedules. At the start of each meeting with participants, care was taken to build rapport.

Nonetheless, the recruitment process meant that most participants were plugged into groups for people with intellectual disabilities, and had social contact and support from other group members and staff. These self-selecting participants are likely to not represent how the wider community of people with intellectual disabilities see themselves. It is noted that out of the charities and third sector organisations approached to take part in the research, participants came from only 23% of the organisations approached. Future recruitment may be improved by forming relationships with more of these groups and possibly increasing contact to reduce scepticism and communicate potential motivators for the study.

5. Online data collection

In view of the Covid-19 situation, meetings with potential participants and data collection were conducted online. Most of the groups of people with intellectual disabilities became familiar with the use of video conferencing platforms over the course of the pandemic. Practically, several participants needed help from staff or carers to set up the video call on their devices, and were then able to work the call on their own. Another benefit to online data collection was that researchers were able to speak with groups around England more conveniently without needing to travel, which meant that more groups and participants could be reached.

Nonetheless, online data collection had its challenges. It was particularly important for researchers to be able to have a gauge of how participants were feeling, especially considering that the questions asked could be emotive and difficult to think about. It was therefore important to check in with participants if they had trusted people they could speak to, and to debrief any difficult emotions after the session well. However, it was my experience that most participants enjoyed the process of thinking about how they saw themselves, and thought of the time positively. I did not come across participants who became distressed by the questions. Another related difficulty faced was in terms of engaging participants who might be more camera shy. Given the importance of gauging participant's mood, it was important for us to be able to see them through the video call, and was something that was hard to compromise on. To resolve this, more time had to be spent in terms of rapport building and use of technology to "hide self-view" in order for participants to feel comfortable and participate in the project.

More hopefully, the Covid-19 pandemic and shift towards online work has shown me how adaptable individuals, including those with intellectual disabilities, can be. In the context of people with intellectual disabilities experiencing digital inequality, due to reasons such as a lack of internet access, limited use of the internet, and having more risks than benefits (Glencross, Mason, Katsikitis, & Greenwood, 2021), the pandemic seems to have pushed a way forward in terms of the usage of the internet. If used well, internet use could facilitate the development of relationships, increase social participation, and reduce social isolation (Sallafranque-St-Louis & Normand, 2017). With education and support, this could be an area service providers could leverage on in supporting people with intellectual disabilities be integrated into current world and culture.

6. Understanding Self-esteem

As my research into self-esteem progressed, I developed a more nuanced view of the construct. In our subjective experience, self-esteem tends to be high when the individual wins a contest, gains acceptance to a social group, experiences victory, but falls when the individual experiences failures. This correlation may lead us to think that self-esteem may not just be the outcome, but also the cause of success and failures in life. For example, someone with high self-esteem may come across as more convincing and thus achieve more. However, delving into the research, the many problems with self-esteem research became apparent. As addressed in the earlier chapters, self-esteem research mainly relies on explicit self-report measures. However, it is likely that people who have a tendency to endorse positive statements about themselves will go on to endorse positive behavioural and social outcomes. Conversely, people who are generally negative about the world, people, and circumstances may go on to endorse negative views about themselves. In this vein, perhaps there is a need for more objective measures of self-esteem in the field. However, given the definition of self-esteem as how an individual perceives their self-worth, it remains uncertain how an individual's perception can be objectively measured outside of themself.

In addition, another issue of note is heterogeneity. Research suggests that people with high self-esteem show more variability in behaviours than for people with low self-esteem (Baumeister, Campbell, Krueger, & Vohs, 2003). For example, high self-esteem is correlated to both the presence and absence of aggression. They suggest that this points to how some of the low correlations between self-esteem and behavioural outcomes conceal the tendency for different types of high self-esteem, such as those with narcissistically high self-esteem, to produce different responses. However, it is to note here that narcissism is fundamentally different from high self-esteem. Narcissism is characterised by feelings of superiority, entitlement, self-centredness, which is unlike self-esteem which refers more to feelings of self-respect and acceptance (Ackerman et al., 2011). Narcissism and self-esteem have highly divergent effects on social relationships, mental health, and antisocial behaviour (Orth & Robins, 2022).

When narcissism and high self-esteem are teased apart appropriately, a recent review has highlighted that self-esteem is indeed beneficial across several important life domains, with these benefits holding across age, gender, race/ethnicity, and controlling for potential third variable confounds (Orth & Robins, 2022). What remains now is more thought and research into developing and implementing interventions for self-esteem, especially for those who have low self-esteem and to consider if self-esteem boosted by interventions will translate into the real world. This seems to be an area of research particularly relevant to individuals with intellectual disabilities, given the levels of discrimination and stigma they unfortunately face in their day to day.

However, I note that this research has led me to question my assumptions about how people with intellectual disabilities see themselves – not all of them have low self-esteem, and in fact many are happy with themselves and their productive lives. I believe that being able to be curious about individual experiences and think more widely about the experiences of people with intellectual disabilities will be of help to me both personally and as a clinician. When working with individuals with intellectual disabilities, or individuals in other stigmatised groups, I would want to be more aware of my assumptions and judgements, and how this would influence the questions I ask, my assessments, formulation, and interventions. For example, if I were to stop assuming that people see themselves poorly, I might then not dismiss what is going well, and help individuals build stronger narratives around their strengths and sense of self-worth.

In terms of self-esteem as a construct, perhaps it might be worth considering if accurate, rather than high self-esteem could be more beneficial. Currently, self-esteem is defined as a perception of oneself, removed from actual evaluation (Baumeister et al., 2003). There perhaps remains argument for tagging self-esteem to a sense of reality and real capabilities, if the logic flows that boosting self-esteem for the sake of self-esteem could lead to people having an inflated sense of self and believing that they could do anything, including undesirable behaviour. In that manner, maybe self-esteem interventions should try to boost self-esteem as a reward for improvement and good behaviour.

7. Conclusion

This critical appraisal sought to reflect on the issues and learning points which arose over the course of this research. Reflections on joint working were offered. Next, reflection on recruitment considered some of the issues that might have meant that our sample was not representative of the population of people with intellectual disabilities. Despite the difficulties of online data collection, it was nonetheless helpful in expanding the reach of the research. It has also evidenced the adaptability of people with intellectual disabilities.

Conceptually, although there is contention in the literature about the construct of self-esteem, and if a more accurate evaluation of the self is a more appropriate measure, it nonetheless remains as a predictor of life outcomes. Self-esteem of individuals with intellectual disabilities is little studied, and remains an area that warrants further research. Taken together these reflections provide learning points for future research in this population.

8. References

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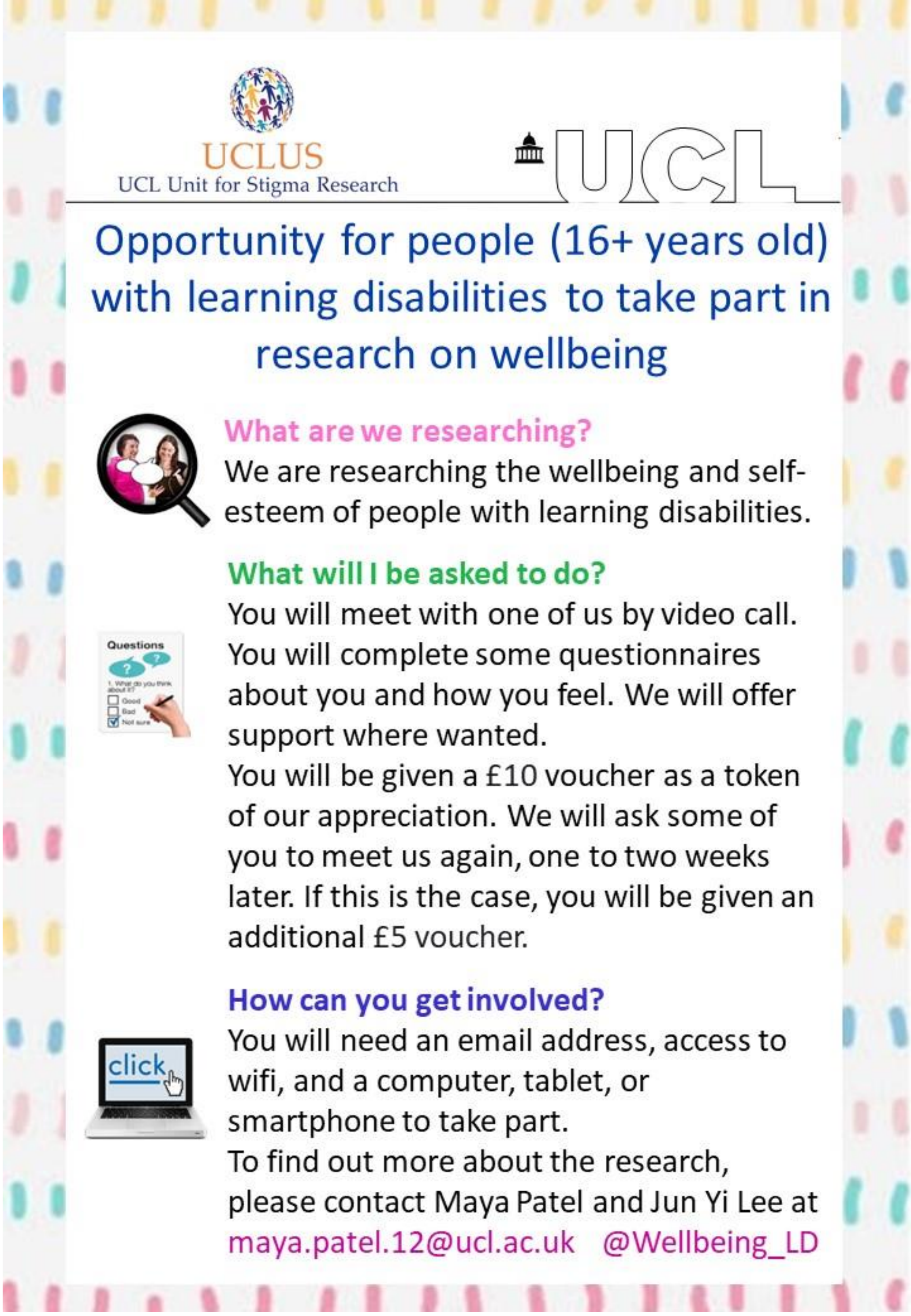
Appendices

1. Appendix A: Recruitment Advert



UCLUS
UCL Unit for Stigma Research

UCL

Opportunity for people (16+ years old) with learning disabilities to take part in research on wellbeing

What are we researching?

We are researching the wellbeing and self-esteem of people with learning disabilities.

What will I be asked to do?

You will meet with one of us by video call. You will complete some questionnaires about you and how you feel. We will offer support where wanted.

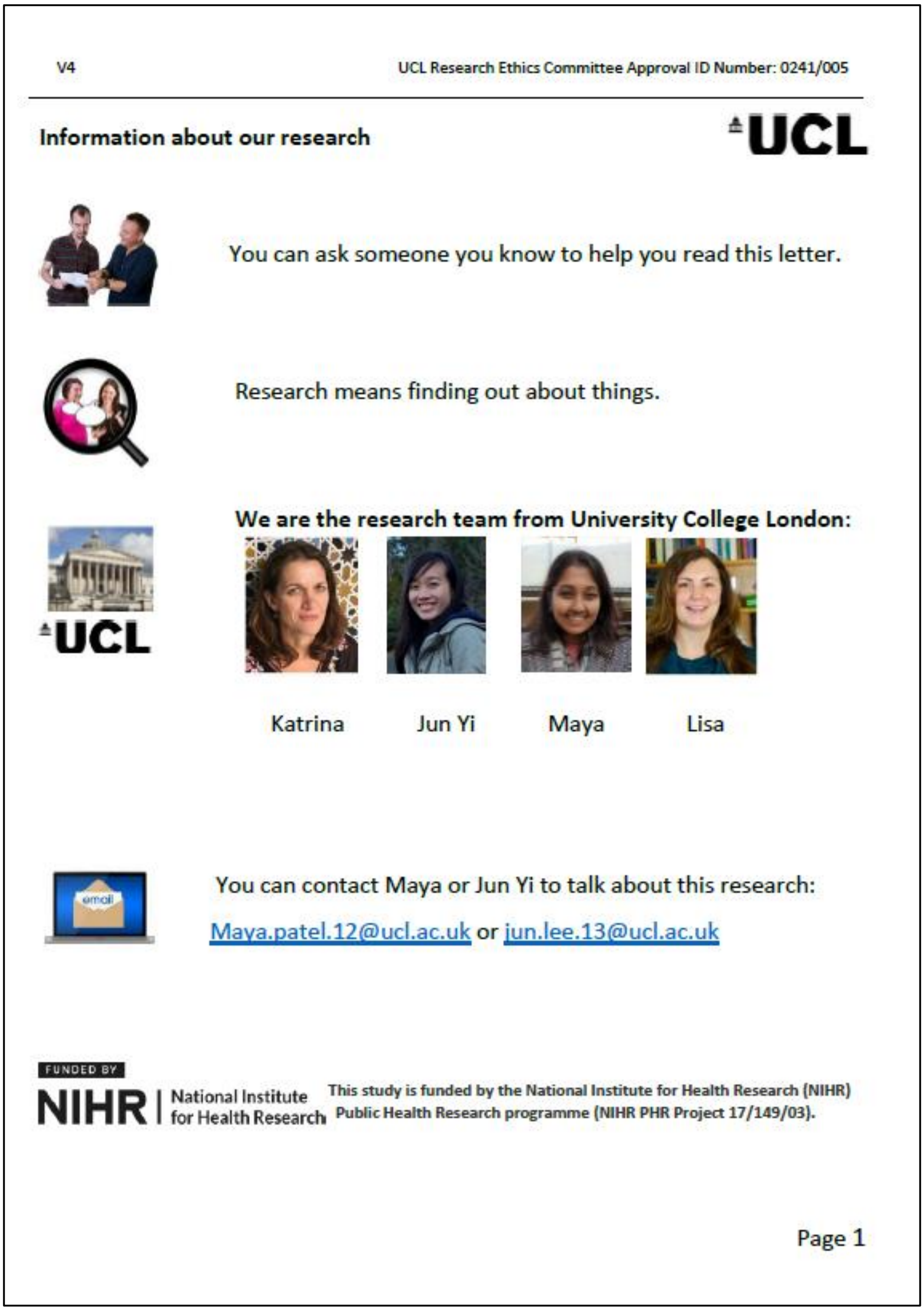
You will be given a £10 voucher as a token of our appreciation. We will ask some of you to meet us again, one to two weeks later. If this is the case, you will be given an additional £5 voucher.

How can you get involved?

You will need an email address, access to wifi, and a computer, tablet, or smartphone to take part.

To find out more about the research, please contact Maya Patel and Jun Yi Lee at maya.patel.12@ucl.ac.uk @Wellbeing_LD

2. Appendix B: Easy Read Information Sheet



V4 UCL Research Ethics Committee Approval ID Number: 0241/005

Information about our research

UCL

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

Research means finding out about things.

We are the research team from University College London:

UCL

Katrina Jun Yi Maya Lisa

You can contact Maya or Jun Yi to talk about this research:

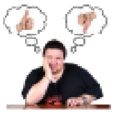
Maya.patel.12@ucl.ac.uk or jun.lee.13@ucl.ac.uk

FUNDED BY NIHR | National Institute for Health Research

This study is funded by the National Institute for Health Research (NIHR) Public Health Research programme (NIHR PHR Project 17/149/03).

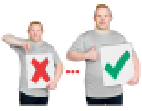
Page 1

Why we are doing this research



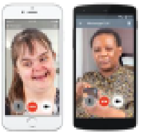
We want to find out how people with learning disabilities think about themselves and how they feel.

We have made a new questionnaire to find this out.



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

We would like you to complete some online questionnaires about you and how you feel.



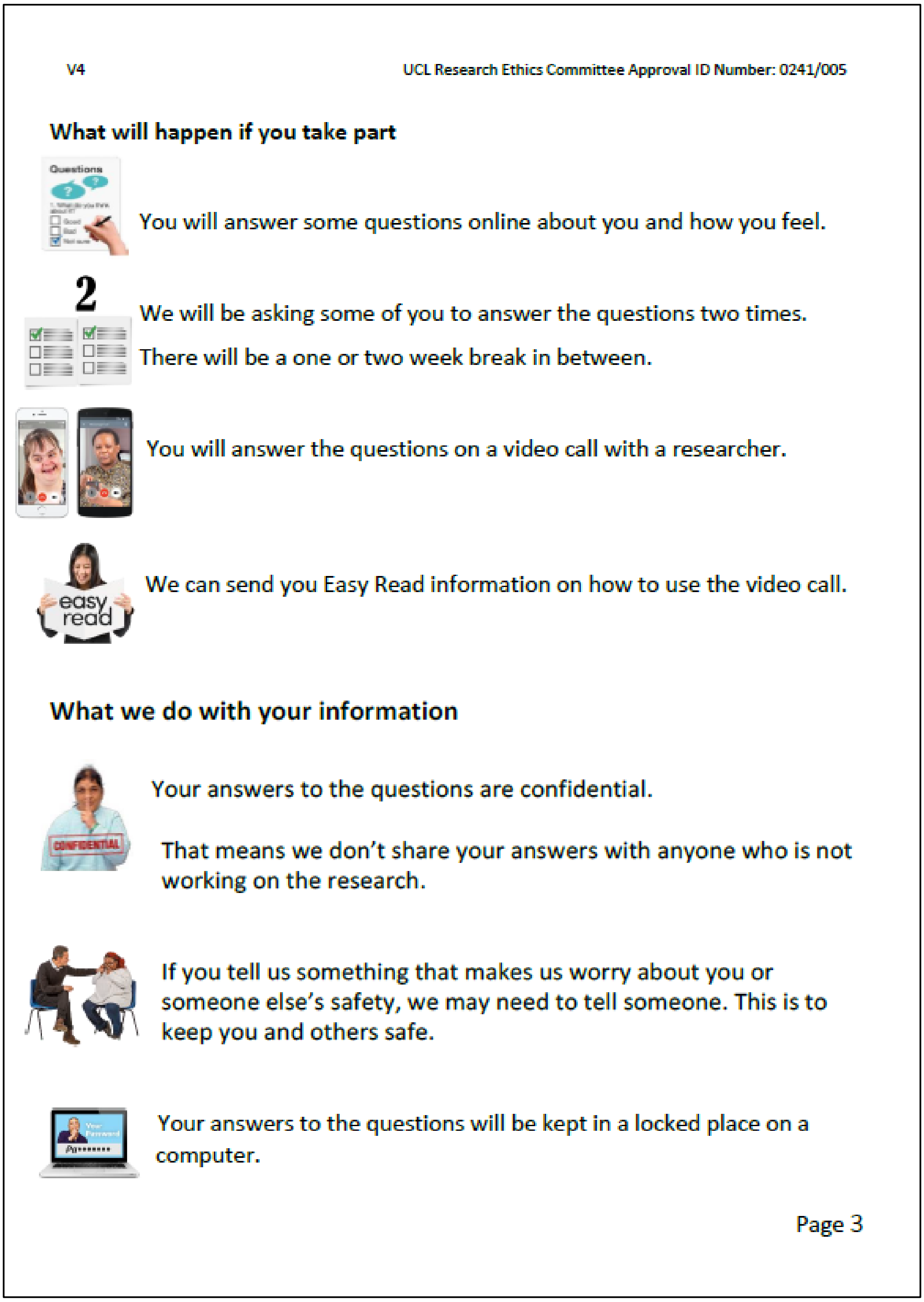
We will meet you using video calls.

A video call means you will see us on a digital computer or phone screen. We will not be together in the same room.

We are asking you to take part

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

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



V4 UCL Research Ethics Committee Approval ID Number: 0241/005

What will happen if you take part

You will answer some questions online about you and how you feel.

We will be asking some of you to answer the questions two times.

There will be a one or two week break in between.

You will answer the questions on a video call with a researcher.

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

What we do with your information

Your answers to the questions are confidential.

That means we don’t share your answers with anyone who is not working on the research.

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

Your answers to the questions will be kept in a locked place on a computer.

Page 3

The computer will use passwords to keep what you talked about safe.

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**.

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

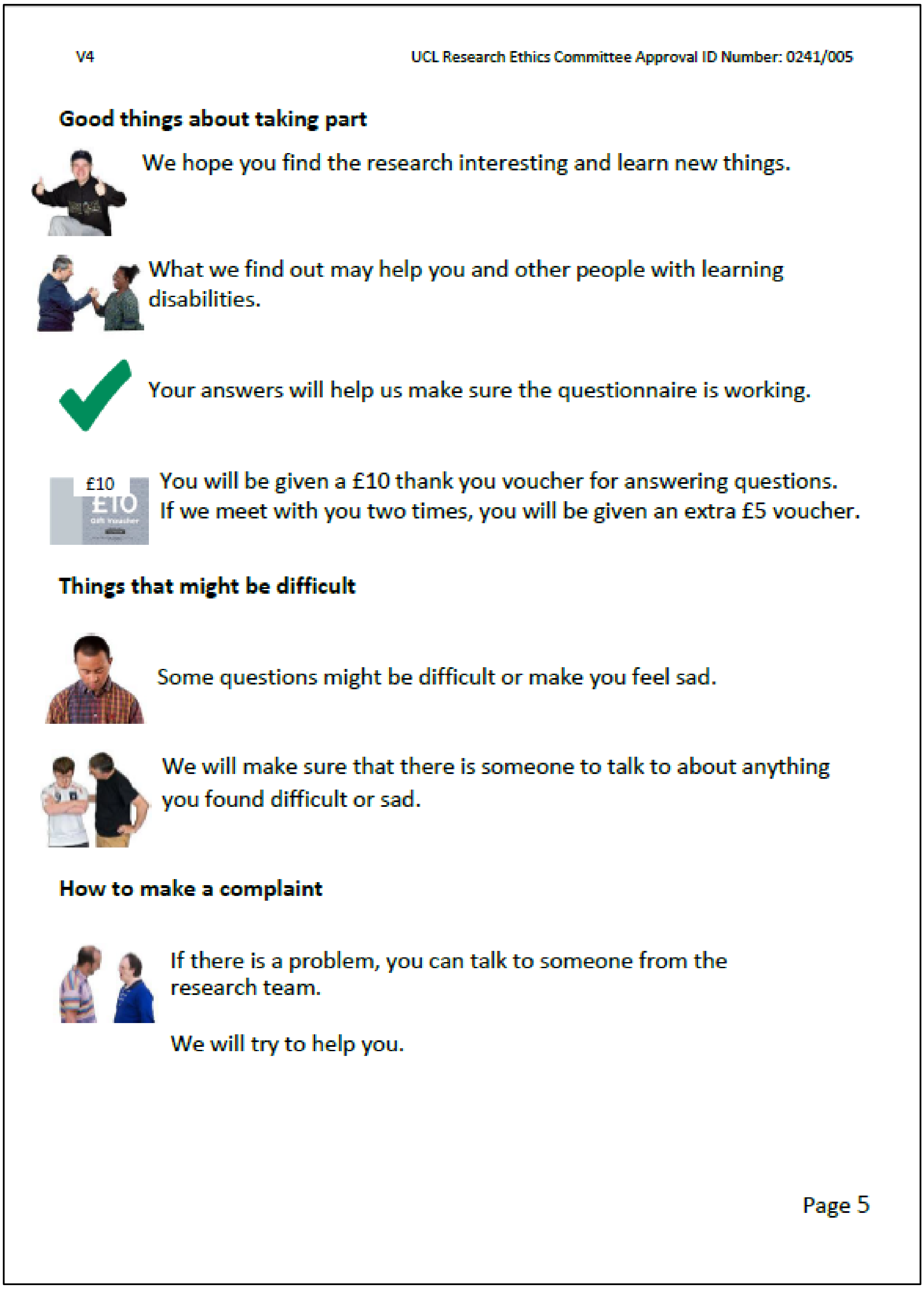
If you say **yes** to the research, we will ask you to give your consent on a video call. We will record this part of the call.

This means that you agree to take part in the research and that you are happy to use your information.

Changing your decision

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

You don’t have to tell us why.



Good things about taking part

We hope you find the research interesting and learn new things.

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

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

You will be given a £10 thank you voucher for answering questions.
If we meet with you two times, you will be given an extra £5 voucher.

Things that might be difficult

Some questions might be difficult or make you feel sad.

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

How to make a complaint

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

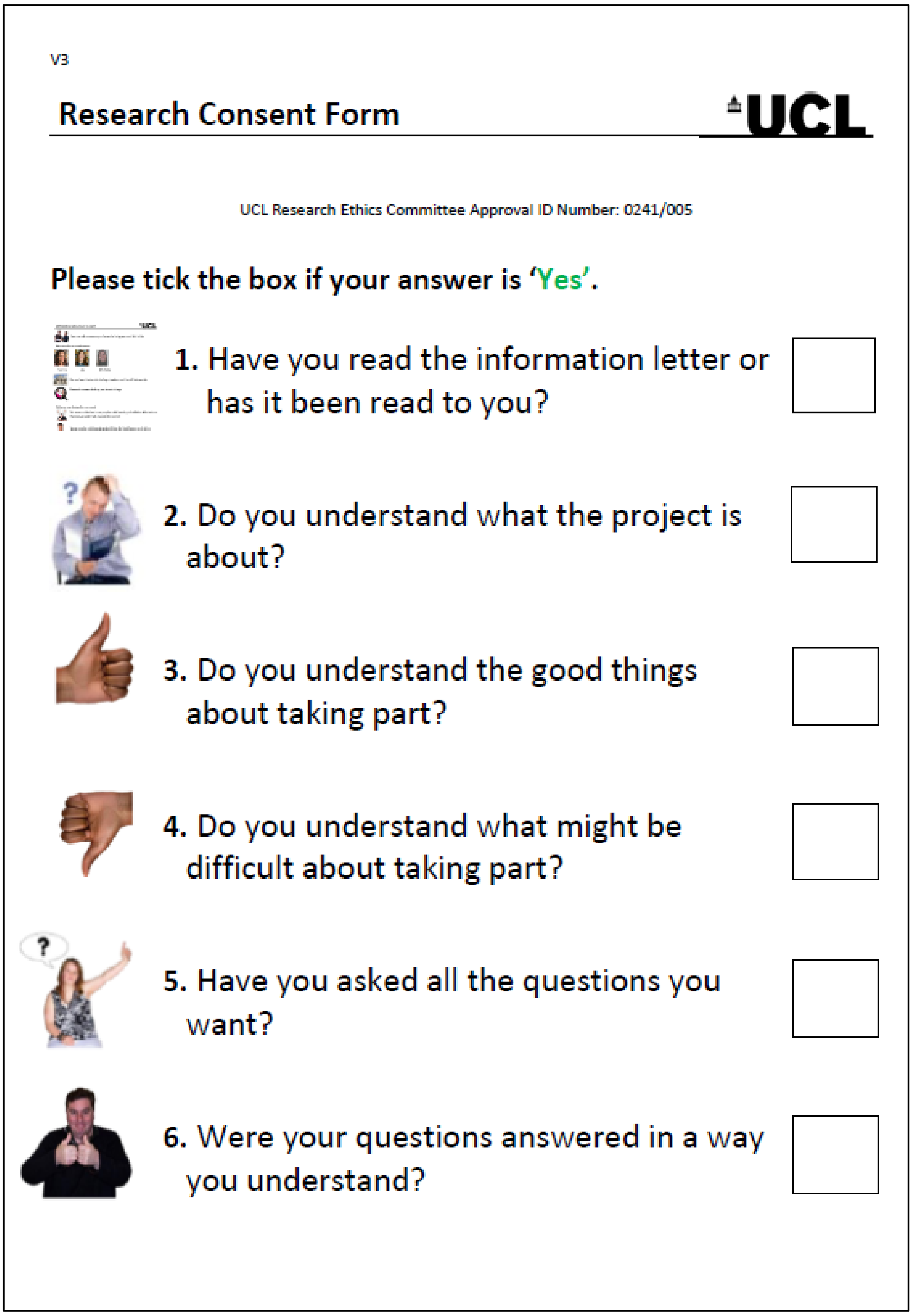
We will try to help you.

Contact details for the research team are on page 1.

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

Thank you for reading about the project.

3. Appendix C: Consent Form



V3

Research Consent Form

UCL Research Ethics Committee Approval ID Number: 0241/005

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

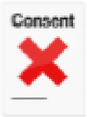
1. Have you read the information letter or has it been read to you? ☐
2. Do you understand what the project is about? ☐
3. Do you understand the good things about taking part? ☐
4. Do you understand what might be difficult about taking part? ☐
5. Have you asked all the questions you want? ☐
6. Were your questions answered in a way you understand? ☐

V3

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

8. Do you understand that we will meet with you either one or two times on a video call? ☐

9. Do you understand that all of the information you give the research team will be kept confidential? ☐



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

11. 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 initials:________

4. Appendix D: Adapted Rosenberg Self-esteem Scale

In general

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

5. Appendix E: Warwick-Edinburgh Mental Wellbeing Scale-ID

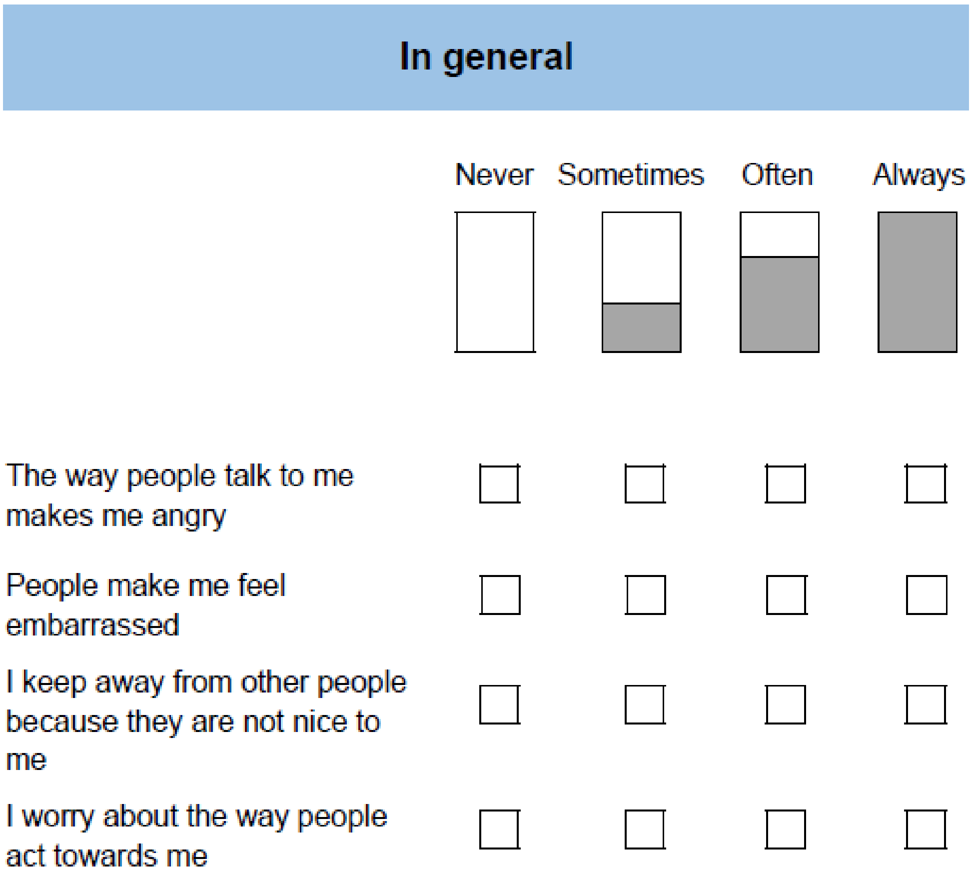
Removed due to copyright

6. Appendix F: Sense of Power Scale

In general

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

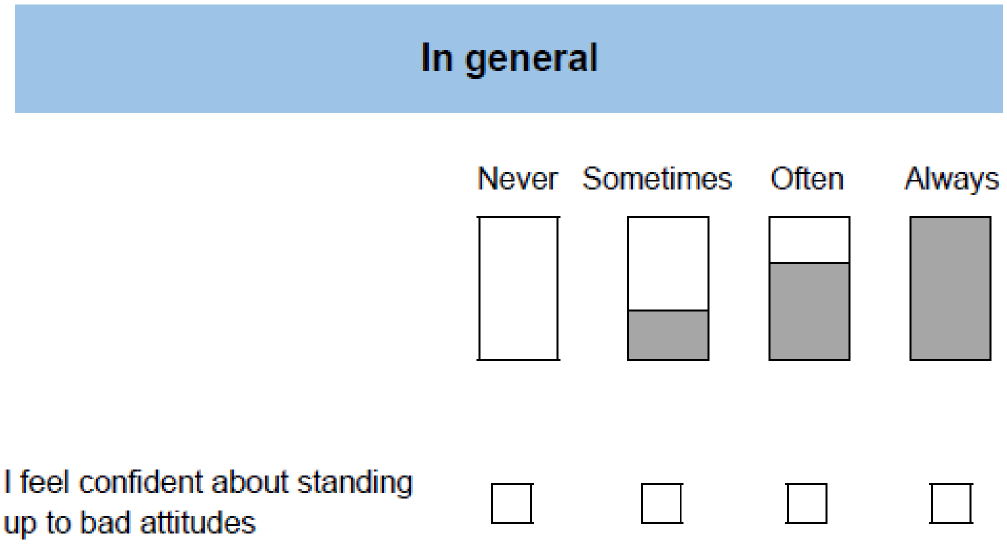
7. Appendix G: Negative Reactions to Discrimination Scale



In general

	Never	Sometimes	Often	Always
The way people talk to me makes me angry	☐	☐	☐	☐
People make me feel embarrassed	☐	☐	☐	☐
I keep away from other people because they are not nice to me	☐	☐	☐	☐
I worry about the way people act towards me	☐	☐	☐	☐

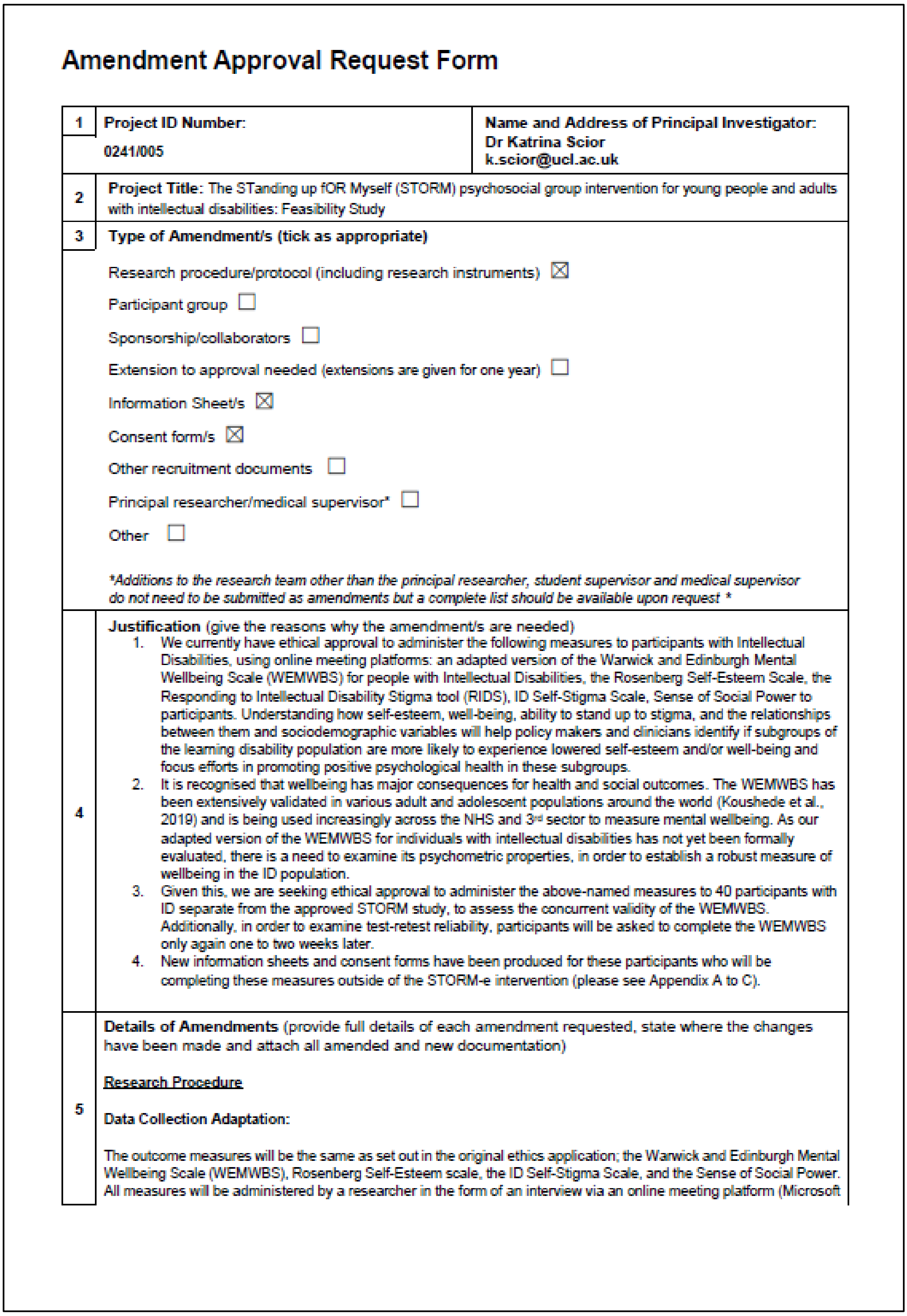
8. Appendix H: Self-efficacy in Rejecting Prejudice



In general

	Never	Sometimes	Often	Always
I feel confident about standing up to bad attitudes	☐	☐	☐	☐

9. Appendix I: Ethics Amendment and Approval



Amendment Approval Request Form

1	**Project ID Number:** 0241/005	**Name and Address of Principal Investigator:** **Dr Katrina Scior** **k.scior@ucl.ac.uk**

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

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

Research procedure/protocol (including research instruments) ☒

Participant group ☐

Sponsorship/collaborators ☐

Extension to approval needed (extensions are given for one year) ☐

Information Sheet/s ☒

Consent form/s ☒

Other recruitment documents ☐

Principal researcher/medical supervisor* ☐

Other ☐

**Additions to the research team other than the principal researcher, student supervisor and medical supervisor do not need to be submitted as amendments but a complete list should be available upon request **

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

1. We currently have ethical approval to administer the following measures to participants with Intellectual Disabilities, using online meeting platforms: an adapted version of the Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS) for people with Intellectual Disabilities, the Rosenberg Self-Esteem Scale, the Responding to Intellectual Disability Stigma tool (RIDS), ID Self-Stigma Scale, Sense of Social Power to participants. Understanding how self-esteem, well-being, ability to stand up to stigma, and the relationships between them and sociodemographic variables will help policy makers and clinicians identify if subgroups of the learning disability population are more likely to experience lowered self-esteem and/or well-being and focus efforts in promoting positive psychological health in these subgroups.
2. It is recognised that wellbeing has major consequences for health and social outcomes. The WEMWBS has been extensively validated in various adult and adolescent populations around the world (Koushede et al., 2019) and is being used increasingly across the NHS and 3rd sector to measure mental wellbeing. As our adapted version of the WEMWBS for individuals with intellectual disabilities has not yet been formally evaluated, there is a need to examine its psychometric properties, in order to establish a robust measure of wellbeing in the ID population.
3. Given this, we are seeking ethical approval to administer the above-named measures to 40 participants with ID separate from the approved STORM study, to assess the concurrent validity of the WEMWBS. Additionally, in order to examine test-retest reliability, participants will be asked to complete the WEMWBS only again one to two weeks later.
4. New information sheets and consent forms have been produced for these participants who will be completing these measures outside of the STORM-e intervention (please see Appendix A to C).

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

<u>Research Procedure</u>

Data Collection Adaptation:

The outcome measures will be the same as set out in the original ethics application; the Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS), Rosenberg Self-Esteem scale, the ID Self-Stigma Scale, and the Sense of Social Power. All measures will be administered by a researcher in the form of an interview via an online meeting platform (Microsoft

	Teams), with support via online screen share, and the researcher entering data into Qualtrics. The WEMBS will be administered at two time points, one to two weeks apart. Information Sheets and Consent Forms Participants will be informed that they will be required to complete one of the measures (WEMWBS) on two occasions, one to two weeks apart. Participants will receive payment in recognition of the time taken to complete the measures, at the second time point. Revised consent forms as well as participant and carer information sheets are included in the Appendices.
6	**Ethical Considerations** (insert details of any ethical issues raised by the proposed amendment/s) For the current amendments, the ethical considerations in addition to those outlined in the previous ethic application and amendment, are as follows: Informed consent will be obtained in the same manner as detailed in the ethics amendment approved on 22/1/2021. Unlike in the STORM study, participants will take part in the research for its own sake and to advance our understanding of psychological wellbeing in people with intellectual disabilities and methods to measuring it reliably. They will be thanked for their participation and given a £15 voucher after the second data collection meeting but will not be entered into the STORM study. In our experience people with intellectual disabilities are keen to contribute to research and to be asked about their experiences and concerns. Furthermore, they will be well supported during data collection, and as in the main STORM study, should they become unduly distressed will be supported in the moment and where necessary further support will be sought from the group facilitator or another familiar supporter.
7	**Other Information** (provide any other information which you believe should be taken into account during ethical review of the proposed changes)

Declaration (to be signed by the Principal Researcher)

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

Signature: [redacted]

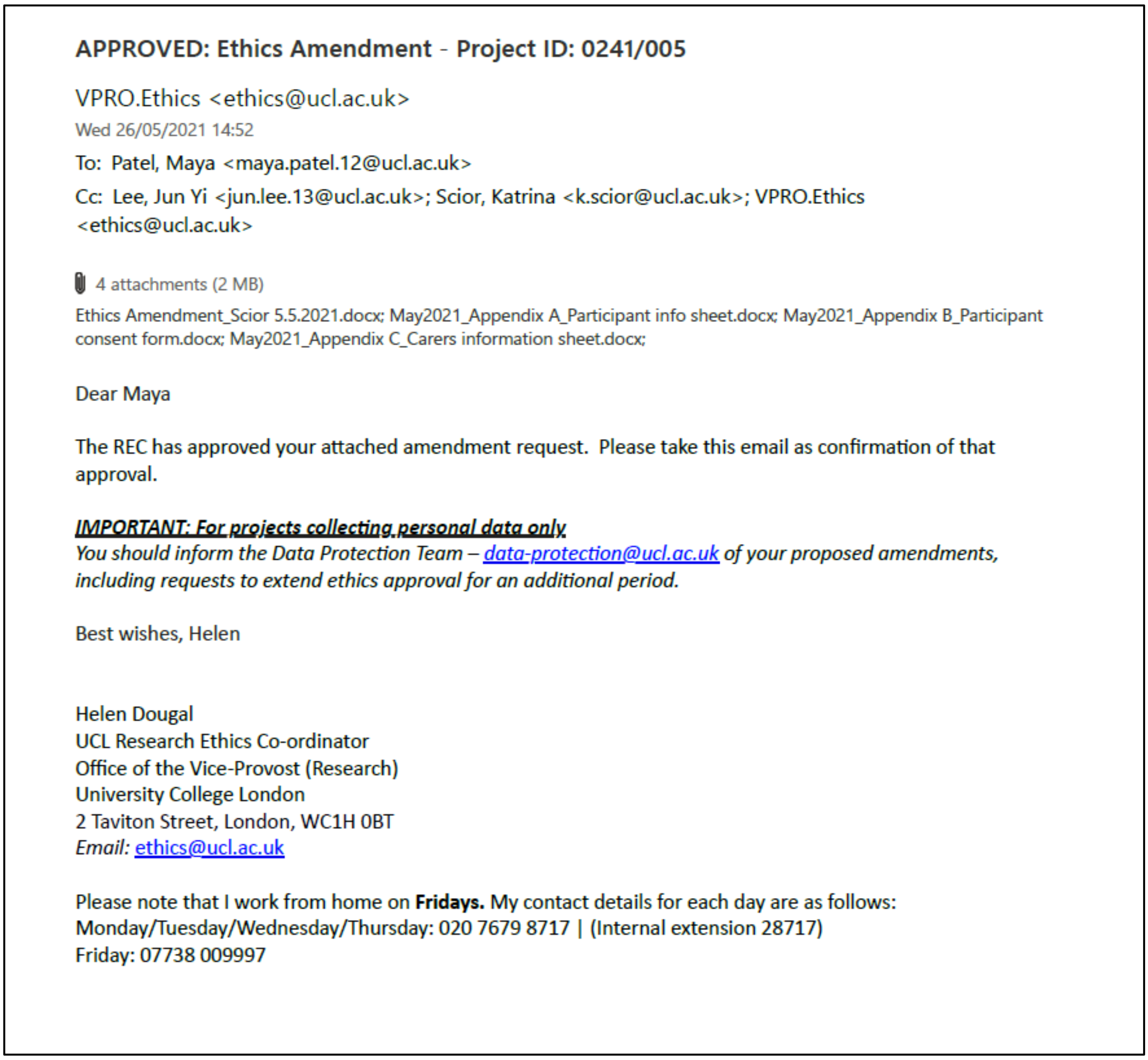
Date: 5.5.2021

FOR OFFICE USE ONLY:

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

Signature of the REC Chair:

Date:



APPROVED: Ethics Amendment - Project ID: 0241/005

VPRO.Ethics <ethics@ucl.ac.uk>
Wed 26/05/2021 14:52
To: Patel, Maya <maya.patel.12@ucl.ac.uk>
Cc: Lee, Jun Yi <jun.lee.13@ucl.ac.uk>; Scior, Katrina <k.scior@ucl.ac.uk>; VPRO.Ethics <ethics@ucl.ac.uk>

Ethics Amendment_Scior 5.5.2021.docx; May2021_Appendix A_Participant info sheet.docx; May2021_Appendix B_Participant consent form.docx; May2021_Appendix C_Carers information sheet.docx;

Dear Maya

The REC has approved your attached amendment request. Please take this email as confirmation of that approval.

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

Best wishes, Helen

Helen Dougal
UCL Research Ethics Co-ordinator
Office of the Vice-Provost (Research)
University College London
2 Taviton Street, London, WC1H 0BT
Email: ethics@ucl.ac.uk

Please note that I work from home on **Fridays.** My contact details for each day are as follows:
Monday/Tuesday/Wednesday/Thursday: 020 7679 8717 | (Internal extension 28717)
Friday: 07738 009997

10. Appendix J: Joint Thesis Contribution Statement

This was a joint thesis project, conducted together with Maya Patel, who was assessing the psychometric properties of the WEMWBS-ID and short WEMWBS-ID for individuals with intellectual disabilities.

The systematic literature review documented in Part 1 was carried out independently. Maya Patel acted as second rater using the Qualsyst framework for the studies, as described in the methodology.

For the empirical study, we jointly submitted the ethics amendment, data protection, risk assessment forms. We jointly developed the Qualtrics survey and research database. Recruitment posters and the study's Twitter account were jointly created and managed. We jointly contacted 57 charities and third sector organisations. I met with 19 participants and Maya met with 25 participants for data collection. All subsequent analyses and writing up were conducted independently.