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# Relating to others: the role of social stressors and social comparisons for individuals with intellectual disabilities

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Submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology

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## **Foreword**

This foreword is included to bring context to the mitigating circumstances around the changes from the originally intended study that was interrupted in March 2020 due to COVID-19. Below is a summary of the intended project and how this was adapted.

Compassion Focused Therapy (CFT) has been found to increase social connectedness in the general population and may help people with intellectual disabilities to develop adaptive coping strategies for social stressors. One component of CFT uses imagery techniques, and these techniques may be less accessible to people with intellectual disabilities due to the cognitive demands of these tasks. Initially, the researcher planned to conduct an exploratory study, using a between-groups design, with three phases; focus group, pilot study and main study (Appendix 2.1). This study intended to investigate the ability of young people with intellectual disabilities to apply a compassionate image to a personally salient social stressor, compared to a group without intellectual disabilities. A secondary aim was to explore the associations between anxiety, self-compassion and social comparison (see Appendix 2.1 for original proposal).

To understand salient sources of social stress for both groups, several focus groups were conducted. These focus groups aimed to explore whether the social stressors reported in the literature resonated with the participants with and without intellectual disabilities. The list of social stressors generated from this analysis would have been used to develop the list of salient social stressors used the main study.

In the main study participants would have had two 1:1 sessions to complete three self-report measures (anxiety, social comparison and self-compassion) and two other tasks (social stressors rank task and the compassionate image “Kind Helper task”) (see Appendix G of original proposal in Appendix 2.1). At the end they would complete the Wechsler Abbreviated Scale of Intelligence (2 Subset) (Pearson Corporation, 2011). In

the social rank task participants would have ranked these stressors in order of salience to them. The Compassionate Image Exercise ('Kind helper' Task) would have helped participants create their ideal compassionate other; a person or animal. Once they had generated a compassionate image participants would have then been asked to imagine themselves in their top social stressor scenario (identified in in the rank task) and asked to use their compassionate image in order to self-soothe any threat response from the social stressor (Appendix 2.1).

Before the closure of all colleges beginning March 2020, the researcher had completed three focus groups with students who have intellectual disabilities (Appendix 2.1 shows a table of the recruitment completed prior to closure). Rather than applying the originally proposed Content Analysis to the focus groups a more in-depth qualitative approach was adopted to examine salient social stressors and is reported in place on the original Major Research Project in Chapter 2 of this thesis.



Institute of Health  
& Wellbeing

## CHAPTER ONE: SYSTEMATIC REVIEW

*The relationship between social comparison, self-concept and emotional wellbeing in individuals with Intellectual Disabilities: A Systematic Review and Narrative Synthesis*

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Prepared in accordance with authors instructions for the Journal of Applied Research in Intellectual Disabilities (JARID) (Appendix 1.1)

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**Abstract**

**Background:** There is growing interest in understanding the mechanisms and interactions of socio-contextual factors on the processes of social comparisons for individuals with intellectual disabilities. This systematic review provides a narrative synthesis of this literature on social comparisons.

**Method:** A computerised search of electronic databases was completed. Ten studies met inclusion criteria for this review. Methodological quality was examined using a quality rating tool and limitations discussed.

**Results:** Synthesising these studies has highlighted current research supporting the hypothesis that negative social comparisons are related to experiences of stigma, lower self-esteem and higher psychological distress.

**Discussion:** This review identified the heterogeneity and infancy of research in this area. Future research could help to clarify the initial findings and continue to identify the underlying mechanisms of these complex relationships. Clinical implications are also discussed.

**Key words:** social comparison, intellectual disabilities, self-concept

## **1 Introduction**

Individuals with intellectual disabilities are among the most stigmatized groups in society (Ali, Hassiotis, Strydom, & King, 2012). Understanding processes of social comparisons for individuals with intellectual disabilities has been highlighted as key to understanding and helping this population manage the impact of stigma on their emotional wellbeing (Dagnan and Waring, 2004).

Social comparison is defined as the process by which we evaluate ourselves, compared to others, in relation to our abilities, values, and other domains of social importance (Festinger, 1954). Three types of social comparisons have been defined; downwards, lateral and upwards. Downward comparison refers to the process of comparing oneself to less fortunate others and presenting oneself as superior (Finlay and Lyons, 2000). Lateral comparison refers to comparing oneself to others with similar ability, thus protecting wellbeing but also creating a barrier to change (Crocker & Major, 1989). Upward comparisons refer to the process of comparing oneself with others one regards as superior on valued aspects of self (Suls & Wills, 1991).

Allan and Gilbert (1995) proposed that downwards (positive) social comparison have positive implications for well-being and help maintain a positive sense of self (self-esteem or self-evaluation), whereas upwards (negative) social comparison are associated with feelings of shame, psychological difficulties and contribute to a negative sense of self. In the general population it has been found that self-concept is associated with choice of social comparison. For example, people with a positive sense of self (e.g. higher self-esteem) have been found to be more likely to make (positive) upward comparisons with people who have greater ability on a given attribute in order to increase their motivation and functioning in this area (see Sulz & Wills, 1991). Since the original theory there has been growing interest in the role of negative social comparison, the impact of this process

on the development of sense of self, and in understanding the mechanisms and interactions of other socioemotional factors (e.g. self-esteem, anxiety and depression) on the processes of social comparisons (Butzer, & Kuiper, 2006). There is particular interest for understanding these relationships for stigmatized populations, such as people with intellectual disabilities (Ali et al., 2015).

Unlike the general population, who often engage in upward comparisons (see Buunk & Gibbons, 2007 & Gerber, Wheeler & Suls, 2017 for reviews) individuals with intellectual disabilities have been found to largely engage in either downward or lateral comparison (Finlay & Lyons, 2000). A proposed reason for this difference is that upward comparisons may present a threat rather than providing a motivation for attainment. Upward comparisons can serve to reinforce the feeling of being devalued in society subsequently exposing vulnerability for stigmatized groups and contributing to a negative sense of self (Paterson et al, 2012). Therefore, rarely making upward comparisons may represent a protective factor to maintain a positive sense of self and socioemotional wellbeing for individuals with intellectual disabilities.

The choice of comparison type (downward, upward or lateral) appears to depend on the source for comparison (e.g. comparing within one's social group to similar peers or out with, to others who may be seen as superior). For example, Finlay & Lyons (2000) found that individuals with intellectual disabilities chose downward comparisons when comparing themselves to those with more severe intellectual disabilities. It has been suggested that this choice of downward comparisons to peers with similar, or more severe, intellectual disabilities is linked to proximity and reduced social networks (e.g. hospitals, residential care, segregated schools) and that this reduction in socialisation with others outwith their peer group may serve as a mechanism to protect the self from the negative effects of stigmatisation by reducing exposure to others with perceived higher ability

(Jahoda & Markova, 2004; Crabtree & Rutland, 2001). This supports the view that reducing exposure to upward comparisons, and preferring downwards comparisons, plays a role in protecting sense of self. When opportunities to compare to those without intellectual disabilities arise individuals with intellectual disabilities have been shown to use lateral comparisons (Finlay and Lyons, 2000). Furthermore, Craig and colleagues (2002) found that individuals with intellectual disabilities highlight the differences between themselves and peers with more severe intellectual disabilities. Conversely, when comparing themselves to others without intellectual disabilities, they found individuals emphasise their similarities suggesting a protective function for stigmatized groups and an active choice to protect the self (Jahoda & Markova, 2004; Szivos-Bach, 1993).

In light of studies highlighting the differences in types of social comparisons for people with intellectual disabilities it would appear relevant to review and synthesise this research that has examined these choices. The review will also report any identified associations between social comparison and sense of self or wellbeing. If associations have been examined the review will also report any research that has examined possible underlying mediators and moderators of social comparison processes using theoretically relevant covariates. To the author's knowledge, the present paper is the first to apply a narrative synthesis to assimilate quantitative research that has investigated social comparisons across clinical and non-clinical samples of young people and adults with intellectual disabilities.

## 2 Methods

### 2.1 Search Strategy

A systematic review was conducted according to guidance set out in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009).

The following databases were searched: MEDLINE In-Process & Other Non-Indexed Citations and MEDLINE 1990 to Present via Ovid, Embase 1990-Present, updated daily via Ovid, and CINAHL 1990 to date via EBSCOhost, PsychINFO 1990 to present via EBSCOhost and ERIC 1990-present via EBSCOhost. All searches were carried out on the 28.10.2019 using the University of Glasgow library service (<http://eleanor.lib.gla.ac.uk>).

Subject headings and keywords were reviewed. Through discussion with NHS and University librarians it was agreed not to include specific associated factors in order to balance sensitivity and specificity. This increased sensitivity allowed identification of studies examining other potential theoretically relevant covariates and ensured any necessary and relevant studies were not excluded. Social Comparison was not an indexed Subject Heading in the majority of databases (Appendix 1.2), therefore, Scope Notes were reviewed for related Subject Terms by the author and librarians. Subject Headings were removed if Scope Notes were not related to Social Comparison. The Author Terms were matched onto database subject headings and the results were combined. The final Author Terms were agreed with the librarians and are detailed in Table 1.1. A full description of the search strategy for each database, including Subject and Authors terms, is included in Appendix 1.2. A subsequent citation search was conducted on eligible articles to identify additional studies not in the electronic search.

**Table 1.1** Author search terms

---

((learning or intellectual\*) N2 disab\*) OR (mental\* N2 retard\*) OR (down\* syndrome))  
AND  
(((social\* N1 (compar\* OR interaction\* OR perception\* OR accept\* OR approv\* OR conform\* OR adjust\* OR understand\* OR identit\*)))

---

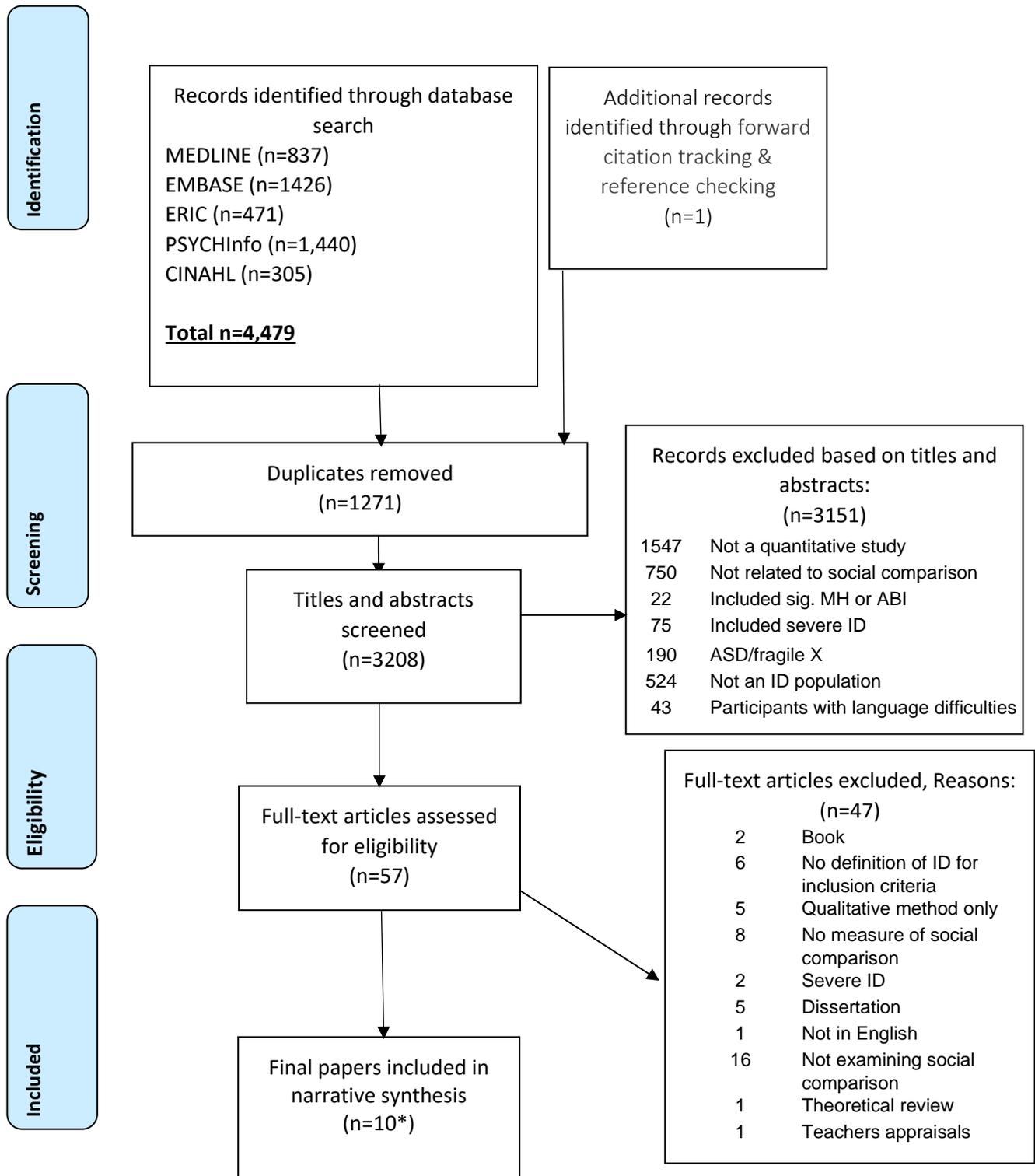
## 2.2 Study Selection

Studies were included if they: (i) were original, peer-reviewed, quantitative or mixed method studies published in English; (ii) used child, adolescent and/or adult clinical and/or non-clinical samples; (iii) examined the relationship of social comparisons to other variables (e.g. self-esteem) is examined as part of the design; (iv) were from any geographic area; (v) measured social comparison; (vi) used a reliable and valid assessment of Intellectual Disabilities (i.e. IQ 70 or below), or the authors explained how participants were diagnosed (e.g. if they used a clinical sample). Studies were excluded if they: (i) were qualitative studies; (ii) discussion papers; (iii) literature reviews; (iv) single case studies/case reports; (v) guidelines; (vi) policy statements; (vii) letters; (viii) books/dissertations.

The participants could be any age, from clinical or non-clinical samples, and there was no restriction on setting (e.g. hospital, residential care, school). Studies including individuals with severe intellectual disabilities or significant language difficulties were not included. Studies were also excluded if their participants had significant mental health difficulties (e.g. psychosis), neurodegenerative disorders (e.g. dementia) or acquired and/or traumatic brain injury, as these could have been possible confounding factors. Those with an Autism Spectrum Disorder or fragile x syndrome were also excluded due to differences in social responding within this group (World Health Organisation, 2010) which may also have been confounding factors.

Databases were searched using the terms outlined above (n=4479). Duplicate articles were deleted using EndNote (<http://endnote.com/>) (n=1271). Article titles and abstracts were read for relevance (n=3208) and inclusion/exclusion criteria applied. Articles were excluded if not relevant (n=3151). The full texts of the remaining articles were read (n=57) and non-relevant articles discarded (n=47). Forward citation tracking was conducted and reference sections were hand searched (n=1). Ten papers, describing nine cross-sectional studies, were selected for the narrative synthesis (Table 1.2). Two papers used the same study (Szivos-Bach, 1993; Szivos, 1991). A PRISMA flowchart of the of search process is provided in Figure 1.1.

Figure 1.1 Flow chart of systematic search process and study selection



**Note:** MH = Mental health, ABI = Acquired brain injury, ID = Intellectual Disabilities, ASD – Autism Spectrum Disorder, \* 9 studies

### 2.3 Data Analysis

It was not possible to conduct a meta-analysis due to methodological variability therefore a narrative synthesis approach was taken to tackle the issue of heterogeneity and to create a synthesis of the findings and limitations (Popay et al., 2006).

### 2.4 Quality Appraisal

The methodological quality rating tool used was the *Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies* (QATCCS) (NIH, 2016) (see Appendix 1.3). The 14-item QATCCS covers three fundamental domains; (1) appropriate selection of participants, (2) appropriate measurement of variables, (3) appropriate control of confounding variables.

Checklist items were rated as *yes*, *no* or *not applicable/could not determine/not reported*. Each *yes* was given a score of 1 and *no* or *not applicable/could not determine/not reported* a score of 0. The total score range was 0-14. A score of 10 or above was rated *good*; 5 or above was rated *fair*; less than 5 rated as *poor*. Scoring was based on reporting in other studies of the cut-offs for QATCCS (Rankin, 2018). Due to the cross-sectional designs of the studies some questions were automatically answered “*No*” or “*N/A*” as per tool guidance (see Appendix 1.3). Appendix 1.4 provides a breakdown of quality appraisal for each study.

Six of the papers (60%) were reviewed by a second rater, to establish the inter-rater reliability. There was 96% agreement across the checklist items, indicating adequate reliability. Differences in opinion were resolved through discussion.

### 3 Results

#### 3.1 Quality ratings of studies

Overall, the quality did not vary a lot across the studies; one study was rated as *poor* and the others rated as *fair* (Table 1.2). Whilst no studies obtained a *good* rating, it is important to note this low rating mostly reflects the limitations of the cross-sectional design rather than a risk of bias. This review acknowledges that this was the best methodology the authors could offer due to the study designs and therefore considered further specific study limitations for quality analysis (Table 1.2). Sample sizes varied considerably across studies and only one study reported a power analysis (Patterson et al., 2012). However, small, cross-sectional studies often do not report this as they are exploratory in nature. According to the QATCCS guidance, this limitation should therefore not be considered a "*fatal flaw*" (Appendix 1.3).

In terms of risk of bias, measures of social comparison were largely consistent. Seven studies used the Social Comparison Scale (Allan & Gilbert, 1995) adapted for people with intellectual disabilities (Dagnan and Sandhu, 1999). The scale measures social rank from domains of rank and achievement, social attractiveness, and group belonging. The lower the score the higher the feeling on inferiority to others and the lower self-perception. A number of studies note that this scale requires further psychometric development due to low internal reliability, therefore, it may not be a valid method to assess social comparison (Dagnan et al., 2004; Cooney et al., 2006). The study rated *poor* (Crabtree et al., 2001) used a Self-Perception Profile for Children (Harter, 1985) to assess social comparison for children aged 8-13 years despite their study age range of 11-16 years. This may therefore have impacted on the validity and reliability of this measure for participants over 14. A Self-Perception Profile specifically for intellectual disability

students (Harter & Renick, 1988;2012) may have been more appropriate for this study population, however, Crabtree and Rutland (2001) make no reference to their decision not to use this in their study. Two studies (Szivos-Bach, 1993; Szivos, 1991) pre-dated the Social Comparison Scale (Allan & Gilbert, 1995) and piloted a measure based on Coopersmith (1967).

### **3.2 Participant characteristics**

Overall, the studies examined 625 participants; 316 (51%) were adults (18 + years), 309 (49%) were children or young people (11-21 years old). Sample sizes were mostly small ranging from 36-151 participants. Two papers used the same sample of participants (Szivos-Bach, 1993; Szivos, 1991) (Table 1.2).

There was a clear split in the study populations. Five studies included children and young people (aged 11-21 years) (O’Byrne et al., 2017; Crabtree et al., 2001; Cooney et al., 2006; Szivos-Bach, 1993; Szivos, 1991) and five studies included adult participants (Dagnan et al., 1999; Dagnan et al., 2004; McGillivray et al., 2007; McMahon et al., 2008; Paterson et al., 2012) (Table 2.1). For this reason, this review will consider the evidence from the studies with adults followed by those with children and young people.

Table 1.2: Study design, sample characteristics and main findings

Studies with adults									
Study, location & quality	Design	Aim/hypothesis	Sample	Assessment of ID	Measure of social comparison	Other measures	Main findings	Limitations	
1  <i>Fair</i>	Dagnan et al, 1999, UK	Cross-sectional	To develop scales suitable for assessing social comparison and self-esteem in people with intellectual disability. Examined the relationship of social comparison with self-esteem and depression.	- Adults - 43 participants with ID (18 females, 25 males) - attended adult training centres	BPVS-Short Form (Dunn et al. 1982).	The Social Comparison Scale (Allan & Gilbert, 1995) Adapted for the study.	- Zung Depression Scale (Zung 1965) - modified Rosenberg Self-Esteem Scale (Rosenberg et al. 1989)	A significant positive correlation was found between positive self-esteem and social comparison on the achievement dimension. Depression significantly negatively correlated with social comparison on the social attractiveness and group belonging dimensions, and with positive self-esteem. Depression was predicted only by social comparison on the social attractiveness dimension.	No control groups. No account of confounding variables. Factor analysis with small sample size. Unable to determine who participants socially compared themselves to.
2  <i>Fair</i>	Dagnan et al, 2004, UK	Cross-sectional	Associations between stigma, self-evaluations and social comparisons	- Adults - 39 participants with mild/moderate ID (18 females, 21 males) - Day centres/ supported employment scheme	BPVS-2 (Dunn et al. 1997)	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999)	- Stigma Scale (Szivos, 1991; Szivos-Bach, 1993). - Evaluative Beliefs Scale (Chadwick et al., 1999).	Stigma correlated with negative self-evaluations and negative social comparisons.	Internal reliability of Social Comparison Scale in study was low  Unable to determine who participants socially compared themselves to.
3  <i>Fair</i>	MacMahon et al., 2008, UK	Cross-sectional Between-groups	Examined the active nature of social comparison. Asked participants to select significant others to compare themselves to.	- Adults - 18 depressed and 18? non-depressed participants with ID (10 females and 8 males per group) - Specialist services for individuals with ID.	Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999)	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999)  Identified Target Social Comparison Scale	- The Glasgow Depression Scale for People with Learning Disability (Cuthill et al., 2003) - The Zung Depression (Zung, 1965 - modified for ID by Kazdin, Matson, and Senatore 1983)	Depressed participants reported significantly more negative social comparisons; the non-depressed group reported that the positive comparisons they made were more salient.	Small Sample size and limited generality due to social circumstances of individuals. Groups not well matched for age or IQ.

						– developed for study		- The Rosenberg Self-Esteem Scale (Rosenberg, Schooler, & Schoenbach, 1989) - modified for ID by Dagnan and Sandhu, 1999)	
4	McGillivray et al., 2007, Australia  <i>Fair</i>	Cross-sectional Between-Groups	Examined the characteristics of mood symptoms and compared individuals without indications of mood disorder with those who display some symptoms and those with significant mood symptoms on level of social support, occurrence of recently disruptive life events, automatic thoughts, self-esteem, and social comparison.	- Adults - 151 participants with mild/moderate ID (68 females, 83 males) - Vocational and supported employment services.	Managers confirmed that participants met the criteria for mild/moderate ID.	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999)	- Beck Depression Inventory II (Beck, 1996) - Reynolds Adolescent Depression Scale (Reynolds, 1987) - Interview for Social Support in mentally retarded adults (Meins, 1993) - The Social Readjustment Rating Scale (Holmes & Rahe, 1967) - Rosenberg Self-Esteem Scale (Rosenberg, Schooler, & Schoenbach, 1989) - Automatic Thoughts Questionnaire— Revised (Kendall & Hollon, 1987)	The depressed group had a significantly lower mean score on social comparison than the ‘at risk’ group and the non-depressed group. A significant difference was found between individuals with and without symptoms of depression on levels of automatic negative thoughts, downward social comparison and self-esteem.	Measures modified for study with no measure of validity or reliability. Created new depression groups post data collection and defined own cut-off points on the depression measure to define groups. Used Adolescent depression scale rather than depression scale for ID population.
5	Paterson et al., 2012, UK  <i>Fair</i>	Cross – sectional Between-Groups	Aimed to investigate = the relationships between social comparison, perception of stigma and self-esteem for people with an ID. Also explored whether social comparison had a moderating effect between perceived stigma and self-esteem	- Adults - 43 participants with ID (25 females, 18 males) - Day centre	BPVS 2nd edn; Dunn et al. 1997)	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999) - adapted further by specifying a target comparison group	- The stigma perception questionnaire (Szivos, 1991) - The Rosenberg Self-Esteem Scale (Rosenberg, Schooler, & Schoenbach, 1989) - modified for ID by Dagnan and Sandhu, 1999)	Stigma negatively correlated with self-esteem and negative social comparisons with the community (but not service users) and positively correlated with psychiatric symptoms.	Broad inclusion criteria. Specific community group limits generalizability. Overlap in self-esteem and social comparison measures. Reliability of Social Comparison Scale low.

<b>Studies with children and young people</b>									
	<b>Study, location &amp; quality</b>	<b>Design</b>	<b>Aim/hypothesis</b>	<b>Sample</b>	<b>Assessment of ID</b>	<b>Measure of social comparison</b>	<b>Other measures</b>	<b>Main findings</b>	<b>Limitations</b>
1	Cooney et al., 2006, UK  <i>Fair</i>	Cross-sectional  Between groups	Investigated social comparisons with disabled and non-disabled peers and future aspirations.	<ul style="list-style-type: none"> <li>- Adolescents (15-17 years)</li> <li>- 32 participants with ID and 28 without ID (29 females, 31 males)</li> <li>- Final year of mainstream and segregated schools</li> </ul>	BPVS – Revised (Dunn, 1997)	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999)	<ul style="list-style-type: none"> <li>- Modified Life in School Checklist – Junior School Version (Arora, 1987)</li> <li>- Experience of Stigma Checklist</li> <li>- Future Aspirations Checklist</li> </ul>	Mainstream group experienced more stigma, especially at school. When asked to compare to severe learning disability peers used downward social comparison. No difference in social comparison scores and aspiration scores in the two groups. No relationship between stigma and future aspirations.	Low reliability of Social Comparison Scale. High refusal rate (50%). Query for reliability of comparisons to a peer without a learning disability.
2	Crabtree et al., 2001, UK  <i>Poor</i>	Study 1: cross-sectional  Study 2: between subject-design	Two studies. Aimed to examine self-evaluation in adolescents with ID and how these adolescents strategically protect their self-concept through use of social comparison.	<ul style="list-style-type: none"> <li>- Adolescents (11-16 years)</li> <li>- Study 1: 145 participants with ID and 145 without –ID (69 females, 76 males)</li> <li>- Study 2: 68 participants with ID (72 females, 73 males).</li> <li>- Special school for children. Non-ID: mainstream schools.</li> </ul>	Statemented as having a moderate Learning Difficulties.	The Self-Perception Profile for Children (SPPC; Harter, 1985) – used in 4 conditions	N/A	Studies suggest that social comparison plays an important role in the process of self-evaluation amongst adolescents with ID.	No IQ measures. Self-Perception scale was designed for use with age range 8-13 years. Unable to determine who participants socially compared themselves to.
3	O’Bryne et al., 2017, Ireland  <i>Fair</i>	Cross-sectional	Examined the role of the level of ID and gender on perception of stigma in individuals with ID who attend a segregated special	<ul style="list-style-type: none"> <li>- Adolescents (12 - 14 years)</li> <li>- 54 participants (21 females, 33 males)</li> <li>- Special needs secondary schools</li> </ul>	Diagnosis of general learning disability	The adapted Social Comparison Scale (Dagnan and Sandhu, 1999)	<ul style="list-style-type: none"> <li>- The experience of stigma checklist (Cooney et al. 2006)</li> <li>- The measure self-perceived stigma (Ali et al. 2008)</li> <li>- Harter’s Self-Perception Profile for</li> </ul>	There was an association between stigma and fewer positive social comparisons such that those who reported greater stigma also reported fewer positive	Unable to determine who participants socially compared themselves to.

			secondary school and whether reports of stigma impact self-perception and social comparison with others.				Learning Disabled Students (Renick and Harter, 1988)	social comparisons with their peers in their special segregated school.	
4a	* Szivos, 1991, UK  <i>Fair</i>	Cross-sectional	Set out a framework for the direct measurement of social comparisons. Also measured self-esteem and stigma.	<ul style="list-style-type: none"> <li>- Adolescents/young adults (16 years - 21 years)</li> <li>- 50 participants (20 females, 30 males)</li> <li>- Further education courses</li> </ul>	BPVS 2nd edn; Dunn et al. 1997)	The Social Comparisons Scale (based on Coopersmith, 1967)	- The Stigma Scale – developed for this study	Most adolescents chose to compare to older same-sex siblings while younger opposite-sex siblings were the least preferred.	<p>Piloted new scales but no reliability measures. No critique of study.</p> <p>Specific community group (students) limits generalizability.</p> <p>Large range IQ which impacts validity of BPVS</p>
4b	* Szivos-Bach, 1993, UK population (paper published in Germany)  <i>Fair</i>	Cross-sectional	Expanded on previous results of the above study. Examined the relationships between social comparisons (friend, other, sibling, ideal), stigma and self – esteem.	<ul style="list-style-type: none"> <li>- Adolescents/young adults (16 years - 21 years)</li> <li>- 50 participants (20 females, 30 males)</li> <li>- Further education courses</li> </ul>	BPVS 2nd edn; Dunn et al. 1997)	The Social Comparisons Scale (based on Coopersmith, 1967)	<ul style="list-style-type: none"> <li>- The Stigma Scale (Szivos, 1991)</li> <li>- Aspirations-Expectations test – developed for this study</li> </ul>	The study suggested that some students may derogate others, especially younger opposite sex siblings, to maintain their self-esteem. Perceived others without ID as superior and rated friends on course (with ID) as inferior	Same as above

Notes: ID = Intellectual Disabilities, , BPVS = British Picture Vocabulary Scale

### **3.3 Study characteristics**

Seven of the nine studies were conducted in the UK (Cooney et al., 2006; Crabtree et al., 2001; Dagnan et al, 1999; Dagnan et al, 2004; MacMahon et al., 2008; Paterson et al., 2012; Szivos, 1991;1993), the others were conducted in Australia (McGillivray et al., 2007), Ireland (O’Byrne et al., 2017). Two studies with young people and two studies with the adult populations used a between-group design to compare to the general population, however, the studies as a whole recruited from specialist settings thus increasing risk of bias and reducing generalisability of the results (Table 1.2)

### **3.4 Synthesis**

The results below detail the findings of the types of social comparisons used and the relationship of social comparison with other theoretically relevant covariates identified across the studies in each group.

#### **3.4.1 Types of Social Comparisons**

Across all the studies only five specified who the participants compared themselves with. In the adult studies MacMahon (2008) addressed this by specifying that comparisons should be made with general ‘others’ or real world targets. They examined depressed and non-depressed individuals and found slight differences between who these two groups chose to compare themselves with. However, they found the choice of target did not make a difference to whether the comparisons were positive or negative. These findings differ from other studies that have found non-depressed participants engage in downward comparisons to protect their wellbeing and self-esteem (e.g. Finlay & Lyons, 2000; McGillivray et al., 2007). Paterson et al. (2011) also examined different comparator groups, asking participants to compare to their peers and to the general populations. They

also reported, contrary to previous research, no difference between social comparisons to peers or the general population. However, the authors propose that this finding may be due to the low reliability of the Social Comparison Scale (Patterson et al., 2012).

In the studies examining the younger population Szivos-Bach (1993) found students selected friends or peers as similar to them and saw others as superior. The author surmises that this suggests a tendency to compare downwardly to a friend who was most like them in order to protect their own self-worth. Cooney et al (2006) also reported a downward comparison towards peers and found that participants struggled to compare themselves to others out with their social groups (i.e. to those who would be viewed more favourably). The authors propose that these observed difficulties support the view that upward comparisons to others presents a threat to self and emotional wellbeing for people with intellectual disabilities (Alan and Gilbert, 1995; Jahoda & Markova, 2004). Overall a number of authors report low reliability of the Social Comparison Scale and note that participants may be responding defensively, due to a perceived threat in being asked to compare themselves to others who are viewed as more able than them in certain domains. From the small number of studies a clear consensus on preferred types of comparison is difficult to establish. These findings also highlight a need for more sensitive methods to be investigated for assessing social comparison in this population.

### **3.4.2 Self-concept and social comparisons in adulthood**

Three studies with adults examined the relationship between self-concept and social comparison (Table 1.2). They found that when individuals with intellectual disabilities make negative social comparisons this negatively correlates with self-esteem.

(McGillivray et al., 2007; Paterson et al., 2012; Dagnan et al. 1999;). McGillivray et al. (2007) compared three groups of participants (non-depressed, at risk of depression, and depressed) and found that the depressed group had significantly lower self-esteem ( $M = 21.09$ ,  $S.D. = .91$ ) than the 'at risk' group ( $M = 24.80$ ,  $SD = 3.63$ ) and the at risk group had significantly lower self-esteem than the non-depressed group ( $M = 27.20$ ,  $SD = 3.07$ ). Dagnan et al., (1999) found that total self-esteem was significantly correlated with the total social comparison score ( $r = - 0.34$ ,  $P < 0.01$ ) and that positive self-esteem and the achievement subscale of the Social Comparison Scale were positively associated ( $r = 0.57$ ,  $P < 0.01$ ). However, neither Dagnan et al., (1999) or McGillivray et al. (2007) asked participants to specify who they were comparing themselves with when completing the study thus making it difficult to identify the role of who they compare to and self-esteem. Paterson et al. (2012) accounted for this limitation by asking participants to compare themselves to both peers (i.e. other service users) and to people in the community. Using this methodology they found that when participant compared themselves to their peers they felt part of the same group but rated themselves as more capable than others and had higher levels of self-esteem ( $r = .4$ ,  $p < .01$ ). Furthermore, the participants who rated themselves as more socially attractive and capable than people in the community had a more positive view of themselves and reported higher levels of self-esteem compared to those who rated themselves as less attractive and capable ( $r = .41$ ,  $p < .01$ ) (Paterson et al., 2012).

### **3.4.3 Stigma and social comparisons in adulthood**

Two studies have explored the relationship between social comparison and stigma. Dagnan et al., (2004) found that stigma is highly predictive of negative evaluative beliefs that, in turn, predicted negative social comparison. They also found stigma was a

predictor of negative social comparison and the strength of this relationship was mediated by their evaluative beliefs Paterson et al. (2012) also examined the moderating effect of social comparisons on the strength of the relationship between stigma and psychological well-being but did not find a moderating effect. They did however find higher levels of stigma were related to negative social comparisons on the dimensions of social attractiveness ( $r = .35, p < .05$ ) and capability ( $r = .34, p < .05$ ) when individuals compared themselves to members of the community, but not other service users (Paterson et al., 2012). Dagan et al., (2004) noted the internal reliability of the Social Comparison Scale in this study was low and that this is likely to have resulted in unreliable or weaker correlations. The scale was then further adapted by Paterson et al. (2012). Therefore the validity and reliability of this scale is likely to have contributed to the different findings of the two studies. Furthermore, Dagan et al., (2004) used core negative evaluations as a factor in their regression, predicting that negative evaluations would mediate the effect of perceived stigma and social comparisons, whereas the moderator analysis used by Paterson et al. (2012) examined stigma and social comparison as predictors with their type of comparisons (peers vs. the community) as groups. These differing approaches to the regressions may therefore account for the different findings and suggests that further research is required to investigate these relationships.

#### **3.4.4 Emotional wellbeing and social comparisons in adulthood**

The three studies (Dagnan et al. 1999; McGillvary at al. 2007; McMahan et al., 2008) which examined emotional wellbeing all looked at depression but differ in whether these were clinical or non-clinical presentations (Table 1.2). The predictive nature of this relationship remains unclear with McGillvary and colleagues (2007) reporting social comparisons were not a significant predictor of depression. However, Dagnan et al.

(1999) found that depression was negatively correlated with the social comparison subscales of social attractiveness and group belonging and that depression was significantly and independently predicted only by social comparison on the social attractiveness dimension. This difference may reflect the difference in the factors used in the regression analysis; McGillvary and colleagues (2007) used the total social comparison score whereas Dagnan and colleagues (1999) used the sub-scales for their model. This should further be interpreted with caution as the adapted social comparison scale only includes one question relating to social attractiveness and the scale has been noted by the author to require further psychometric development due to low internal reliability therefore may not be a valid method to assess this variable (Dagnan et al., 2004). McGillvary and colleagues (2007) also acknowledged that their finding that social comparison was not a significant predictor of depression was potentially due to the inclusion of self-esteem in their regression model. They conclude that, due to the overlap in social comparison processes and self-esteem, putting self-esteem in their model may have accounted for much of the variance that might have been explained by social comparison.

### **3.4.5 Self-esteem and social comparisons in children & young people**

Finlay and Lyons (2000) propose that using downward or lateral comparisons is a process by which groups who have an awareness of their stigmatized social status, such as those with mild intellectual disabilities, can construct and maintain a positive self-concept. In support of this hypothesis the study by Szivos-Bach (1993) found that young people who had the greatest awareness of stigma from their peers had the lowest self-esteem. Crabtree et al. (2001) also found that when young people with intellectual disabilities were asked to compare themselves to young people without an intellectual disability (viewed as a

non-stigmatized group) their self-evaluation lowered, again offering some support for Finlay and Lyons (2000) hypothesis (Table 1.2). These studies may also offer further evidence for Finlay and Lyons (2000) proposal that self-worth might not be automatically related to being in a stigmatised group but that being in a social environment, where individuals can socially compare, downwardly, or laterally, to similar peers, may play an important role in the development and maintenance of self-worth in this group. These socio-contextual factors (e.g. reduced access to social networks) may serve to protect them from the negative consequences of upward comparisons with others in wider society (Finlay and Lyons, 2000; O’Byrne et al., 2017). However, these studies had a number of limitations and should be interpreted with caution (see Table 1.2).

#### **3.4.6 Stigma and social comparisons in children & young people**

Szivos-Bach (1993) found students who perceived the most stigma also perceive themselves as the most inferior to their comparison targets (non-intellectually disabled other, siblings and ideal self’s). Similarly, O’Byrne and colleagues (2017) found those who reported greater stigma reported fewer positive social comparisons with their peers in their segregated school and their self-evaluations lowered when they were asked to compare themselves to adolescents without an intellectual disability. Cooney et al., (2006) also measured stigma and social comparisons rating in their study however did not look at the associations between these (Table 1.2).

## **4 Discussion**

The small number of studies makes it difficult to confirm a population level difference in social comparison choice for people with intellectual disabilities compared to the general population but offers tentative support that the use of (positive) downward comparison is

preferred for this group and this appears to cut across ages and stages. These studies offer support to the proposal that (negative) upward comparisons may increase psychological threat and serve to negatively impact self-concept by lowering self-esteem, and possibly result in increased feelings of exclusion and stigmatisation (Finlay & Lyons, 2000). They also support the theory that downward social comparisons offer a protective mechanism against stigma and upward social comparisons produce a threat to self (Craig et al., 2002). However, the quality ratings were relatively low, and the cross-sectional nature reduces the ability to make causal conclusions of associations.

#### **4.1 Methodological limitations and future research**

Cross-sectional design was the predominant reason for the lower quality ratings, therefore, additional higher quality studies, such as longitudinal or experimental, are recommended to further explore the robustness of the association between social comparison and other theoretically relevant covariates. The role of social comparison in the development of the young people's perceptions of self and socioemotional wellbeing also requires further investigation due to the heterogeneity of these studies (Table 1.2). None of the studies with young people looked at associations with depression and no studies examined anxiety as a covariate. This may be particularly relevant in further education settings during transitions to adulthood, where awareness of differences to non-intellectual peers may increase threat to self-evaluation, reinforce stigma, and negative comparisons, particularly for individuals with mild intellectual differences.

To establish the robustness of the mediating or moderating effect of covariates, future studies should seek to psychometrically validate measures of social comparison with this population. Furthermore, not controlling for other covariates limits the understanding of possible underlying mediators and moderators for social comparison in

this population and on measures of related concepts, such as self-esteem, the overlap in these processes is likely to impact the investigation of predictive relationships (McGilvery et al., 2007).

This review has numerous limitations including the broad search strategy used to increase sensitivity. This may have returned a higher number of irrelevant studies than required. As social comparison research and intellectual disabilities appears to be in its infancy, the search strategy may not have included all studies which pertain to social comparison, especially if not explicitly measured. In intellectual disability research there is an array of qualitative literature, however this review did not include qualitative research.

#### **4.2 Clinical Implications**

Considering the relationships between social comparison and theoretically relevant covariates (e.g. stigma and self-esteem) it appears important to assess and target intervention strategies. Replicating the findings demonstrating associations between social comparison and emotional wellbeing with wider clinical groups would help to inform potential adapted interventions for those with diagnosed mental health conditions (e.g. depression). From this review it would seem relevant for these interventions to focus on self-esteem, feelings of shame, and the impact of stigma. Cognitive Behavioural Therapy (Pert et al., 2013) has been adapted for this population and Compassion Focused Therapy (CFT) has a particular focus on self-esteem and shame based process. Further research in these approaches may help to foster positive socioemotional well-being and resilience for individuals with intellectual disabilities (Clapton, Williams & Jones, 2018; Clapton et al., 2017).

### **4.3 Conclusions**

Synthesising these studies has highlighted the relationships between negative social comparisons, increased stigma, lower self-esteem and higher psychological distress. It also highlights this population's difficulty comparing upwardly and a tendency to compare downwardly or laterally to protect the self. This review has identified the heterogeneity and infancy of research in this area; therefore, future research is needed to clarify the underlying mechanisms of these complex relationships. This would also help develop clinical interventions which are sensitive to these processes and understand the dual role of social comparisons in offering protection of self-esteem, whilst also exposing a vulnerability to negative self-evaluations for this population.

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## Institute of Health & Wellbeing

### **CHAPTER TWO: MAJOR RESEARCH PROJECT**

#### *Social stress and resilience in college students with mild intellectual disabilities: A thematic analysis*

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Prepared in accordance with authors instructions for the Journal of Applied Research in  
Intellectual Disabilities (JARID) (Appendix 1.1)

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## **Plain English Summary**

**Background:** Research suggests that even small, everyday stressors (e.g. relationship difficulties, work stressors, health worries) have a negative impact on mental health and increase risks of anxiety and depression (Tennant, 2002). People with intellectual disabilities (learning disabilities) are more likely to experience stressful life events than people in the general population and report social situations, such as arguments and bullying, cause them the most stress (D'Angelo & Wierzbicki, 2003). Social situations have been found to be more stressful for young people with intellectual disabilities. However, much less research exists examining social stressors these young people face and little is known about effective psychological therapies to help them cope with stress.

**Aims:** This study aimed to ask young people with intellectual disabilities, at college in the UK, what social situations they found stressful. We also asked them about what helped them cope with social stress.

**Methods:** Thirteen college students with intellectual disabilities (aged 18-23) took part in three focus groups about their experiences of social stress. The focus groups were audio-recorded and analysed using Thematic Analysis.

**Results:** The analysis found five themes. The young people had a good understanding stress, they talked about finding relationships with peers and family difficult and worries about how they would manage these social stresses in the future. They talked about their difficult past experiences of being bullied and stigmatized at school and how this had made them feel lonely and scared. At the moment they seemed to be enjoying college and the support from each other. They talked about the ways they coped with stress both on their own and with other people's help. They also spoke about

how online gaming helped them to have positive social interactions and that this helped them meet more people they could be friends with.

**Conclusion:** Overall it seemed the young people were very aware of their negative past experiences of social situations and this has had a lasting impact on their confidence and stress in social situation. The fear that they might be victim to further social stress, through bullying or stigmatizing behaviour from others in the future, was a big worry. It is hoped that by finding out what these young people find stressful in social situations we can design psychological interventions to help them cope with these stressful situations in the future as they move into adulthood.

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**Abstract**

**Background:** People with intellectual disabilities report similar everyday life stressors as the general population; however, they rate social stressors as having a significant negative impact on their wellbeing. This study investigated salient social stressors experienced by young people with intellectual disabilities.

**Method:** Data was collected from thirteen college students with intellectual disabilities during three focus groups and analysed using Thematic Analysis.

**Results:** Five themes were identified: understanding stress, pressure of increased responsibilities, stigma and exclusion, the company of others: fears and worries, support and resilience. The participants reflected on past and present sources of social stress and communicated their worries about social stress in the future.

**Conclusion:** This study highlights the impact of social stress for these young people. It also identifies their understanding and coping skills. Future research could trial adapted psychological therapies with this population to help them manage these social stressors.

**Keywords:** Intellectual disability, social stress, college students, transition

## 1 Introduction

Stressful life events are widely cited as negatively impacting psychological wellbeing. Emerging research suggests that even small, everyday stressors (e.g. relationship difficulties, work stressors, health worries), negatively impact on long-term mental wellbeing (e.g. Asselmann, Wittchen, Lieb, Hofler & Beesdo-Baum, 2016). A recent study estimates that, in the UK, people with intellectual disabilities are around ten times more likely to experience severe mental health difficulties compared to the general population (Perera, Audi, Solomou, Courtenay & Ramsay, 2020). Furthermore, people with intellectual disabilities are more likely to be exposed to stressful life events (Hughes-McCormack et al., 2017) that contribute to mental health difficulties such as depression (D'Angelo & Wierzbicki, 2003). A plethora of research has examined stressful life events and psychopathology in the general population (Tennant, 2002). However, despite their increased risk and vulnerability, less research exists examining social stressors for people with intellectual disabilities.

The current literature suggests that sources of stress for people with intellectual disabilities are similar to the general population. However, one difference is that individuals with intellectual disabilities repeatedly cite negative social interactions and interpersonal difficulties as the most salient form of stress they encounter (e.g. Lunskey & Benson, 2001; Fogarty & Cummins, 1999). These social stressors appear to have an increased negative impact on the psychological wellbeing of individuals with intellectual disabilities, in comparison to individuals in the general population (Hartley & MacLean, 2005, 2008, 2009).

Research with people who have intellectual disabilities has found that higher levels of social stress are associated with lower self-efficacy and self-esteem, alongside increased feelings of loneliness and hopelessness (Heiman., 2001; Dagnan & Sandhu,

1999). Social stress may have a greater impact on individuals with intellectual disabilities due to smaller social networks, less autonomy in social decision making, and more experiences of social exclusion, stigma, and marginalisation than those without disabilities (Ali, et al, 2012; Dagnan & Jahoda, 2006). Communication difficulties, experience of social exclusion and reduced networks of support have been found to erode people's social confidence, whereas, positive social support has been found to be an important protective factor in relation to mental wellbeing (Lunsky & Benson, 2001).

Another protective factor against the impact of social stressors is the ability to develop ways to cope with these stressors. Hartley & MacLean (2008) investigated coping strategies used by individuals with intellectual disabilities compare to those without. They found that individuals with intellectual disabilities use more non – coping (maladaptive) strategies than their peers, such as hitting someone back when faced with bullying (Hartley & MacLean, 2008). These strategies are considered maladaptive as they often exacerbate social stressors. This appears linked to a struggle to learn, apply, and maintain positive coping strategies and increases vulnerability to the negative psychological impact of social stress (Hastings Hatton, Taylor, & Maddison, 2004; Rittmannsberger, Kocman, Weber & Lueger-Schuster, 2018).

Although social stress is a source of stress across the lifespan young adults are consistently found to be particularly vulnerable to the negative psychological impact of social stress (e.g. O'Shea, Spence, & Donovan, 2014; Low et al., 2012). This is thought to be partly due to increasing demands and responsibilities associated with the transition towards adulthood, which may have a negative impact on young people's self-esteem and social confidence (Hudd et al., 2002; Duell et al., 2018). This transition to adulthood is seen as challenging for all young people, however, it seems to be particularly challenging for young people with intellectual disabilities (see Young-Southward, Philo

& Cooper, 2017 for a review). One area of support for this group can come from accessing further education. However, less individual support is provided in further education compared to schools, with students expected to take greater responsibility for managing their workloads, developing relationships, and managing peer or family difficulties (Forte, Jahoda, & Dagnan, 2011). Furthermore, transitions for young people with intellectual disabilities often span a longer timeframe, with continuing reliance on family members for support creating increased stress and highlighting a divergence from peers without intellectual disabilities at this stage of life (Hudson, 2003; Forte et al., 2011).

Given this is a critical time of increased stress and social demands this study examined social stress in college students with intellectual disabilities. Knowing what these stressors are could contribute to ensuring that sensitive and timely support is provided as these young people transition into adulthood (Perera et al., 2020). The aim of this study was to build on previous research by identifying current salient social stressors for young people with intellectual disabilities attending further education colleges. A secondary aim was to explore their understanding of the concept of stress and their ability to cope with social stressors. This study will focus on social stress and use term 'stress' or 'stressors' when referring to social stress.

## **2 Methods**

### **2.1 Design**

This study used Thematic Analysis (Braun and Clarke, 2006), for three focus groups, to explore the salient social stressors experienced by further education college students with mild intellectual disabilities.

## 2.2 Participants

Participants were recruited from a Supported Learning Department (for individuals with additional support needs), at a further education college in Glasgow, UK. Participants had to be able to give informed consent, be aged 16-25 years, and be identified by education authorities as having an intellectual disability. Individuals who were currently receiving treatment for mental health difficulties (e.g., psychosis, anxiety, or depression) were excluded, as were individuals with significant physical or sensory impairments that would inhibit their ability to take part. This exclusion criteria was presented in the study information sheets and verbally discussed with each individual prior to consent being obtained. Staff identified appropriate individuals and were asked to use the following items from the Adaptive Behaviour Scale-RC:2 (Nihira, Leland & Lambert, 1993) to ensure participants had sufficient receptive and expressive language: ‘Talks to others about sports, family, group activities; Sometimes uses complex sentences containing *because, but*; answers simple questions such as *What is your name?* or *What are you doing?*’.

Table 2.1 provides an overview of the participant characteristics from the background information sheet (Appendix 2.7). One participant did not wish to provide demographic information. Across the UK people with intellectual disabilities are at increased risk of exposure to ‘social determinants’ of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination (Emerson, Graham, & Hatton, 2006; Emerson et al., 2012). In Scotland there is a high level of social and economic deprivation and these socio-economic hardships have been found to add multiple stresses for families; contributing to reduced social opportunities, increased interpersonal difficulties and feelings of stigma, isolation, and exclusion for the whole family (see About Families report, 2012). Due to the role of socio-economic deprivation

on factors such as social stressors, stigma, and wellbeing, it was decided to include a measure of deprivation based on participants postcodes. The Scottish Index of Multiple Deprivation looks at the extent to which an area is deprived across seven domains: income, employment, education, health, access to services, crime and housing (Scottish Government, 2020). Overall participants had a mean age of 19.12 years, lived at home with family, and mostly lived in deprived areas.

Table 2.1: Participant demographics

Participant demographic information ( $n = 12$ )		
Gender	Male	7
	Female	5
Age	Mean (SD)	19.12 (1.34)
	Range	18-23
Deprivation Score	Mean (SD)	1.92 (1.44)
SIMD Quintiles	Range	1-5
Living Situation	Lives Alone	0
	With family	12
	Partner	0
	Flatmate	0
	Supported Accommodation	0

Note: SIMD = Scottish Index of Multiple Deprivation, SD = Standard Deviation

### 2.3 Focus groups

Prior to the focus groups, the researcher reviewed existing literature concerning social stressors (e.g. Lakey, Tardiff, & Drew, 1994; Bramston et al., 1999; Hartley & MacLean, 2005, 2008, 2009; Forte et al., 2011). These previous studies guided the development of a list of social stressors (Table 2.2) and a discussion guide was developed to (Appendix 2.8). The guide covered questions about their general views of stress (e.g., *What do you think are the biggest stresses in your college?*). It also asked participants what others find

stressful (e.g., *What do other students tell you they find stressful?*) and how they coped with social stress (e.g., *How do you cope with these stresses? What helps?*). Students were also asked to identify what social stressor was most salient to them (*Of all the things we have discussed today, what would you say are the most important issues for you?*). Questions were asked flexibly, rather than verbatim, to develop a dialogue within the group and stimulate discussions based on their experiences.

Table 2.2: List of stressors generated from literature

Social stressors highlighted in the literature	
1	Family (e.g., fights or arguments)
2	Relationships (e.g., romantic relationships)
3	Friendships (e.g., making friends)
4	Bullying (e.g., being bullied by others or a friend being bullied)
5	Appearance (e.g., worrying about how you look)
6	Meeting new people (e.g., starting a new course or meeting a new student)
7	Class discussions (e.g., talking in front of others)
8	Staff (e.g., talking to tutors/staff in college)
9	Loneliness (e.g., not having people to talk to in college)
10	Social gatherings (e.g., going to a party with other students)
11	Not being supported (e.g., not having support from others in social situations)
12	Getting in trouble at college (e.g., being told off by staff)

## 2.4 Procedure

Staff identified three classes, totalling thirty students, who were completing an accredited Scottish Credit and Qualifications Framework Course. Two class levels were considered appropriate; Skills for Work National Level 3 and 4. The National Level 3 and 4 courses develop skills and knowledge in specific subject areas, and skills for learning, life, and work. Following the completion of the level 4 courses, students may progress onto the

next level or seek employment opportunities (see <https://scqf.org.uk/> for full framework). The level 3 students can progress into level 4 (staying within the Supported Learning department), therefore, there is less focus on gaining employment following this course. All students were provided study information (Appendix 2.5). Sixteen students consented to participate in the study; eight from the level 4 class and eight from across the two level 3 classes.

The researcher met with identified students in a group setting at their college. The aim of the meeting was to give potential participants a chance to ask questions and provide them with a participant information sheet (see Appendix 2.4). Those interested in participating completed a participant reply sheet (see Appendix 2.5). Participants were reminded that they were under no pressure to participate and that withdrawal, at any time, would not impact any college related activity. Students who completed a reply sheet were then contacted to arrange an individual face to face meeting within a private room within their college. In this meeting the researcher checked their understanding of the study information, answered any questions, reviewed the study Privacy Notice and asked individuals to provide written consent if they wished to continue (Appendix 2.6). Sixteen participants consented and the level 4 class requested to be split into two focus groups.

Prior to the focus group the researcher spent time in the college and again reminded participants of their right to withdraw. This was considered particularly important due to the emotive nature of the topics. The researcher was actively aware at all times of any potential distress which may have been caused through participation in the research. Prior to the focus group beginning all participants were informed they could take a break or leave the group at any time. Two participants opted to do this at the start of two of the focus groups. As per the protocol, the researcher offered a debrief to the participants who left, however they requested support from their college lecturers. The

facilitator was informed that the two participants did not report any adverse effects and, they didn't contribute to the group discussion, therefore this didn't affect the data. After consenting, one student could not participate due to illness. The total number of participants in the analysis was subsequently thirteen.

The focus groups took place in a classroom at the college to maintain familiarity and confidentiality. Each group lasted approximately 45 minutes. The focus groups were recorded via Dictaphone (with prior consent) and transcribed verbatim.

## **2.5 Data Analysis**

An inductive and semantic thematic analysis approach was chosen for data analysis. This epistemological approach allowed for exploration of the individual experiences, meanings, and the reality of participants social stressors. The six steps set out by Braun and Clarke (2006) were followed for the thematic analysis. This involved familiarisation with the data through transcribing the focus groups and reading the transcripts several times before beginning to highlight data related to the study aims. The three transcripts were re-read for initial codes, and themes were identified from the data, and from the researcher's reflective notes. A full transcript was reviewed by two authors (S.M-R and AJ) to ensure the rigour of coding, followed by coding of the entire data set (see extract Appendix 2.9). All codes were collated into a master coding template (see extract Appendix 2.10), and all transcripts were re-analysed. Care was taken to ensure that the content of the themes was grounded in the original data. Discussion with the research team resulted in further changes and final themes (Appendix 2.11).

## **2.6 Reflexivity**

Due to the principal researcher's clinical training, and previous clinical roles working with people with intellectual disabilities, the researcher acknowledges that their clinical experiences will have contributed to the group discussions, the way the researcher analysed the data and the themes that are reported. Whilst there was a topic and discussion guide the researcher was keen to not intervene in the group discussions and allow conversations to develop in order to generate an account of the participants lived experiences. It was also important to the researcher that the students felt comfortable in the group and did not feel that the researcher was overly directive. The researcher was keen to ensure the participants were aware that this was not part of their college class and that the researcher was not viewed as a lecturer or authority figure attached to their education in order to create a feeling of a 'safe space' in the groups. To facilitate transparency during the analysis the researcher took notes of key decision points, reflections on what stood out overall, the flow of conversations, and tension or disagreements within the group. These notes were used to ensure identified themes were consistent with the overall narrative flow. The researcher referred to these notes, alongside transcripts, to provide reflection during theme identification and to try and ensure that it was the participants' voices as the focus of the research, rather than preconceptions the researcher had before looking at the data. This process of keeping the participants view at the focus of the data analysis led to the development of each theme. Following initial identification of themes two research supervisors checked the developing themes to further ensure reflexivity.

## **2.7 Ethical considerations**

Ethical approval was sought and accepted through the University of Glasgow College of Medicine, Veterinary & Life Sciences Ethics Committee (Appendix 2.4) and the colleges provided a letter of access for the researcher. All participants provided informed consent to the use of anonymised quotes. A minor amendment was issued to include participants with intellectual disabilities and autism spectrum disorders (ASD) as this group formed a considerable proportion (approx. 60%) of students at all colleges which were approached for recruitment into the larger study.

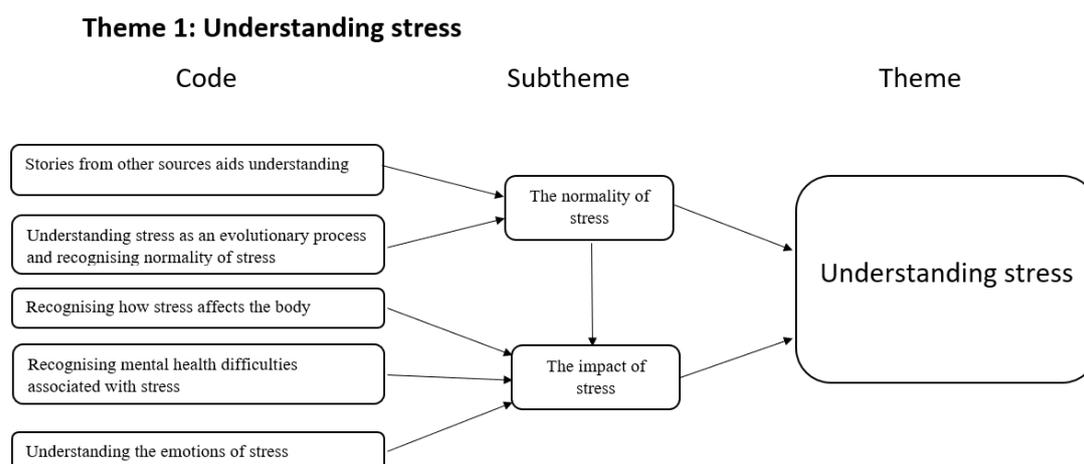
## **3 Results**

The analysis identified five themes (understanding stress, pressure of increased responsibilities, stigma and exclusion, the company of others: fears and worries, support and resilience), and thirteen subthemes. Each theme has a supporting thematic map showing how the researcher developed them from the data. The themes are discussed and illustrated with verbatim extracts from the interviews. (...) indicates that some text has been omitted, and [ ] brackets words that have been inserted. Pseudonyms were created for anonymity.

### **3.1 Understanding Stress**

Figure 2.1 below illustrates how the subthemes link to the theme Understanding Stress. This theme was identified from initial discussions about what general stress meant to each group. As participants had discussed this topic in their classes, they were eager to share their understanding; this led to a more elaborate discussion of what stress meant to them and how they personally experienced this.

Figure 2.1: Thematic map for Understanding stress



### 3.1.1 The normality of stress

Throughout the discussion, several participants referred to the normality of the stress response; that it is an instinct, and that everyone experiences it. One participant demonstrated an in-depth understanding of the evolutionary function of stress:

*I'd say branching off of the natural feeling thing it's like an instinctual thing...  
That animals evolve for survival but nowadays it's just something that's almost just nagging (Jane, aged 18, group 1, Level 4)*

The facilitator was keen to convey the normality of stress to help the group feel relaxed about describing their own experiences (Appendix 2.1). Other group members normalised stress too. For example, in response to a group member who spoke of their stress when talking in front of others, one participant reflected back that this response was normal:

*...I think most people would have worried about talking to others, talking in front of others (Craig, aged 19, group 2, level 4)*

Other group members gave examples of family members, or famous people, who struggled with stress, again highlighting this normality. Overall these discussions seemed to set the scene for each group and created a shared understanding that appeared to help students feel comfortable sharing their own experiences. This also appeared to help the groups understand the role of the facilitator to guide discussion and to use the groups as a space for their own reflections and thoughts.

### **3.1.2 The impact of stress**

Despite recognising stress as normal, the participants reflected on the negative consequences of stress. The students listed associated feelings, such as being nervous, overwhelmed, pressured, scared, and vulnerable. They were aware of potential physical symptoms of stress (e.g., feeling sick, blushing) and the potential longer-term impacts on health (e.g., increased blood pressure or heart conditions). One participant reflected on his experiences of this:

*When I was, well this situation caused me so much stress that I physically stopped eating and seeing my friends for the longest time (Ben, aged 19, group 1, level 4)*

Overall, there was an understanding that, if a person did not know how to manage the feelings of stress, it could become overwhelming and lead to mental health difficulties:

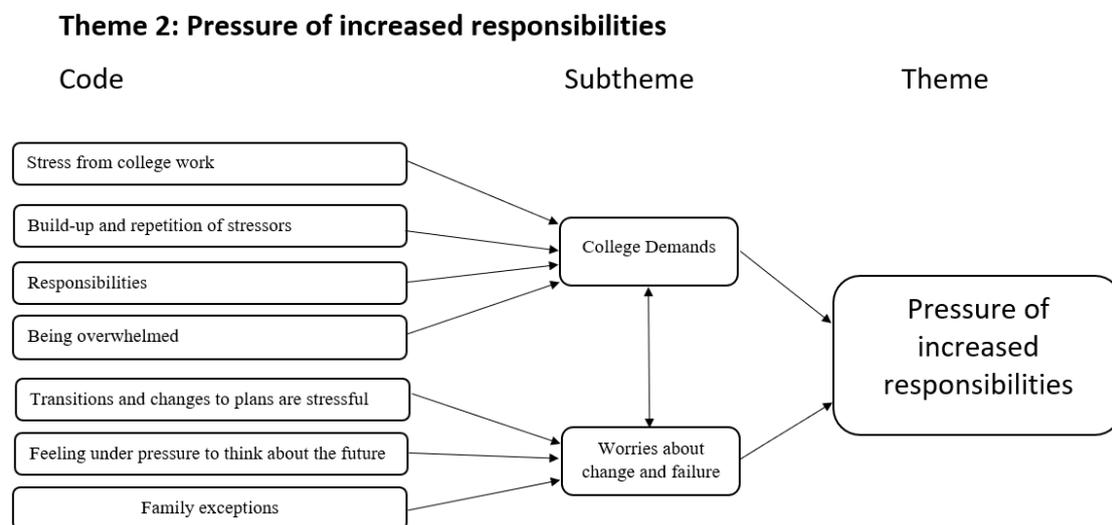
*'Cause, see if you think about it, see if you're not talking much what's wrong with you, it, it, it's like you're bottling up all that anxiety and if you're bottling that up it can, probably, cause something like depression, because you're not speaking about it (Craig, aged 19, group 2, level 4)*

### 3.2 Pressure of increased responsibilities

Figure 2.2 below illustrates how the subthemes link to the theme Pressure of Increased Responsibilities. All three groups described a cumulative pressure from multiple sources; peers, family, and college. One participant highlighted this feeling:

*...and it's all this piling up... I'd say it actually does, it builds on the previous stress* (Jane, aged 18, group 1, level 4)

Figure 2.2: Thematic map for Increased pressure of responsibilities



#### 3.2.1 College demands

Some repeated stressors appeared to derive from daily demands in college; the burden of taking on roles and responsibilities independently, timekeeping/changes in plans and meeting deadlines. They also highlighted social demands; supporting peers, meeting new people, not understanding tasks, and arguments. Some of these pressures appeared to be associated with the social challenges of making the transition towards adulthood. For example, one participant talked about the pressure of social difficulties in a romantic relationship combined with stress of college demands:

*...and it wasn't just her that was causing me stress it was everything else on top of it and then her saying that ...and I couldn't, I didn't have enough ... Plus with exams coming up I was ready to just quit, just stop ...like know how, too much pressure (Ben, aged 19, group 1, level 4)*

### **3.2.2 Worries about change and failure**

These various sources of stress in education seemed to build up over time for participants, beginning in high school when they had to choose their college course. These choices highlighted a worry about making wrong decisions.

Worries about future employment or education were particularly evident in the level 4 group, potentially due to their course being focused on increasing employability. They voiced fear about their future and that *they* [school and college] *are forcing you to look ahead* [and] *it's terrifying* (Ben, aged 19, group 1, level 4). These worries about failure appeared to link with a negative social comparison to others. One participant stated that he was stressed about what courses to pick after level 4, the impact this might have on his future, and his belief that he will be negatively judged if he doesn't succeed:

*... I'm struggling with some, which course I want to pick and how it's going to impact my life... just don't want people to say like "aw, you, you don't have a degree or something and you can't get this job," or I don't want people to say "I'm too stupid" too. (David, aged 19, group 1, level 4)*

The level 3 group focused less on the expectation of getting employment, perhaps reflecting a difference in course focus described earlier. However, these participants did

highlight worries about transitions to adulthood and new social situations. One participant spoke about a new experience of a Universal Credit interview (government payment for living costs) and how socially stressful this was:

*I had a financial one and 'at was for my PIP... it was quite nerve-wracking the first time... I think it was someone I didn't know before and all these complicated questions (Emily, aged 19, group 3, level 3)*

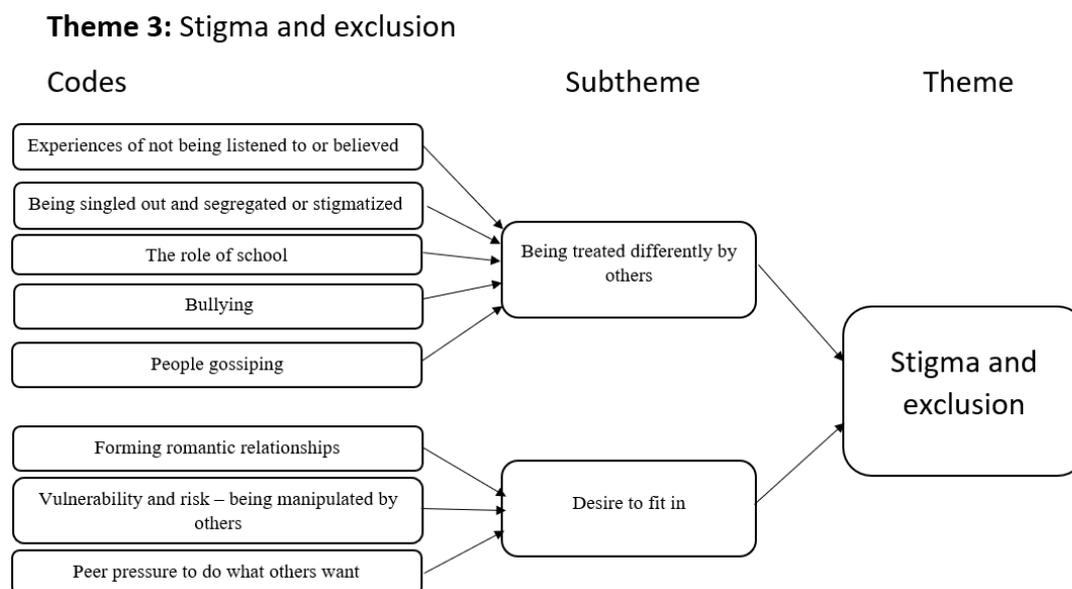
Recognising that money was a source of social conflict for others in their lives appeared to highlight the role of socio-economic deprivation and contribute to an anxiety about social conflicts arising from financial concerns in the future; as illustrated here:

*'Cause money's a really stressful thing...and with money can also. Conflict can happen between friends and family (Craig, aged 19, group 2, level 4)*

### **3.3 Stigma and exclusion**

Figure 2.3 illustrates how the subthemes link to the theme of Stigma and exclusion. Participants consistently reported being singled out, ignored, and treated differently by peers, teachers, and family. Again the group appeared able to use the space provided to discuss how their past experiences had led them to find relationships with others challenging. This appeared to impact on the present by creating worries and stress about potential new social encounters and a pressure to 'fit in'.

Figure 2.3: Thematic map for Stigma and exclusion



### 3.3.1 Being treated differently by others

Negative past social experiences at school seemed significant across the groups. Namely being bullied by others, not being listened to or believed, or being stigmatised and segregated due to their difficulties. One participant shared the emotional impact of being bullied and talked about in school:

*I overheard that someone was talking about me ‘cause I was too ugly and that kind of hurt me (David, aged 19, group 1, level 4)*

Another participant went onto talk about how past bullying increased his hypervigilance to how others perceive him when out in public with his family:

*It’s, it’s the same when I’m going out with mum, dad, ma sisters, I get stared at an’ I hate it I wish, I wish... I know why they staring at me, ‘cause ma eyesight (Thomas, aged 19, group 3, level 3)*

Stresses from social situations were also highlighted when participants spoke about comparing themselves negatively to peers, whom they perceived as more skilled and confident in managing social interactions. Past experiences of not being listened to, or believed, created a sense of learned helplessness and hopelessness in relating to others:

*Mostly, I'm afraid about speaking my mind and no one else is going to care and also they will just believe anyone, anyone who's coming up with confidence, anyone who's got, like, good social skills, they know what they are doing they have good education and they just twisted it. (David, aged 19, group 1, level 4)*

While most group members thought that physical bullying didn't happen in college, they did talk about the adverse effects of gossip and harassment. The role of gossiping was debated across the groups. One group concluded that gossiping started as two people discussing someone without them knowing. That escalates to rumours, and stigmatization, similar to school experiences as described by this participant:

*You gossip, and then it spreads into rumours cause when you gossip to someone, they'll spread it, and then it'll turn into a rumour, and then people start staring at you (Charlotte, aged 19, group 3, level 3)*

Overall being treated differently seemed to have reduced in college and there was a sense that staff offered support. However, the participants still seemed aware of how others may marginalise them, out with college or in the future, and the negative emotional impact of this.

### 3.3.2 Desire to fit in

Pressure from peers seemed relevant for all participants. This pressure revolved around past experiences of exclusion, combined with the desire to fit in with peers (Figure 2.3). One participant highlighted the sense of vulnerability in this desire to gain peer acceptance:

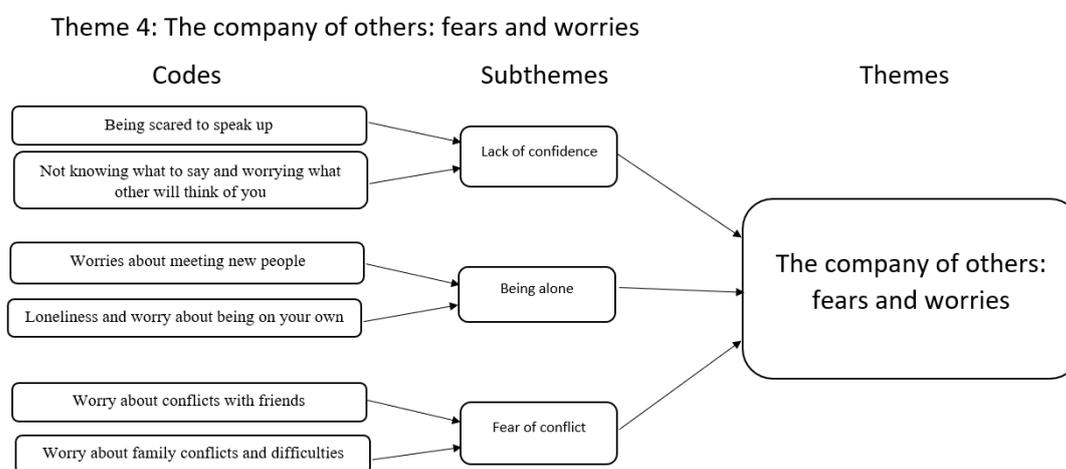
*You want to fit in, so you adapt to like what they like, and you do what they do...even though you don't like it (Ben, aged 19, group 1, level 4)*

This was an emotive topic, however, the trust which group members felt in each other was evident by their willingness to share individual experiences of peer difficulties. Difficulties managing romantic relationships in particular seemed to be a frequent source of social stress and shame for the participants. One participant stated *'cause if you think about it some people feel like they need to be in a relationship in college* (Craig, aged 19, group 2, level 4). Participants identified their lack of social understanding as a risk factor and a vulnerability to being potentially manipulated by others, creating feelings of embarrassment and shame for some members in the group.

### 3.4 The company of others: fears and worries

Figure 2.4 below illustrates how the subthemes link to the theme The company of others: fears and worries. There was a sense that individuals appreciated social company, saw the benefits of relationships, and valued friendships and family. However, in addition, participants voiced concern and trepidation around being with others. This concern seemed to create a sense of loneliness and stress in social situations.

Figure 2.4: Thematic map for The company of others: fears and worries



### 3.4.1 Lack of social confidence

The group members described their previous negative experiences of social interactions at school culminating in a current lack of social confidence. There was a consensus that meeting new people made the majority of group members nervous. This nervousness linked to a worry about saying something wrong or being appraised negatively by others, as explained here:

*When you want to say something but you're not confident about it, but ye still wanna say it anyway... ye know, outcome might be bad or good... it's like, you vaguely know somethin' but you don't want to say it just in case it's wrong, but you want to say it anyway, just in case (Charles, aged 19, group 3, level 3)*

This worry about what others think appeared to contribute to a fear of asking for help and speaking in front of others. This was identified by several participants as their most significant source of stress. Asking for help did appear easier in college than school for

example, one participant commented it felt *relieving* to be allowed to ask for (Jane, aged 18, group 1, Level 4) and there was a sense that, with support from others, their confidence was increasing in college:

*... and mostly, I'm afraid about speaking my mind ...it was stressful for me for asking for help, but I'm still, I'm still, [I'm] getting there (David, aged 19, group 1, level 4)*

### **3.4.2 Being alone**

Whilst college seemed to offer a supportive environment, historic negative experiences with others (e.g. at school) appeared to have lessened their trust in seeking support from others to cope with stress. This difficulty with trust may have been compounded by a perceived lack of understanding from family or teachers and a lack of friends to offer peer support. Overall this created a sense of loneliness. One participant described how anxious her negative experiences of school made her feel and how lonely she felt about being unable to share this with anyone who understood:

*I will say that I've really, really like bad with social anxiety, especially in secondary school, mainly cause I didn't have anyone really to talk to, and I couldn't really relate to my parents or my dad, mm, that was really difficult for me to even discuss it. Even with my teachers because you know there is a difference between how adults experience it or remember, and how, children or teenagers who are currently going through it experience it (Jane, aged 18, group 1, Level 4)*

Many participants talked about feeling segregated or ignored in college. This led to feelings of loneliness:

*'Cause sometimes that when other people are talking over each other, somebody can be lonely when they want to be part of it but then just keeping her, keeping him or her out of it (Emily, aged 19, group 3, level 3)*

Other participants concurred that they experienced social exclusion at school, however, some individuals felt that being alone was not as much of a problem now they are in college and students are *bound to find someone that you [they] know* (Ben, aged 19, group 1, level 4).

This disagreement perhaps suggests that, for some students, being at college has alleviated some of the stress and anxiety around social interactions and provided a space that fosters trust and mutual understanding of each other's experiences.

### **3.4.3 Fear of conflict**

The lack of confidence voiced by some group members seemed to link with fears of conflict with others (Figure 2.4) and a lack of self-efficacy in terms of knowing how to resolve disputes. For example, some participants talked about being involved in, or witnessing, arguments and disagreements with peers caused stress. One participant highlighted that this could be overwhelming:

*well one point last year there was a bit of a fight going on, and I tried to work, and it was too overwhelming, and I had no choice but to leave the classroom cause*

*some people were starting fighting, with words, and it was kinda too, it was too much to bear* (Emily, aged 19, group 3, level 3)

Some participants also spoke about family conflicts causing stress and one participant highlighted her worries about the impact of family conflict on the family dynamics in the future:

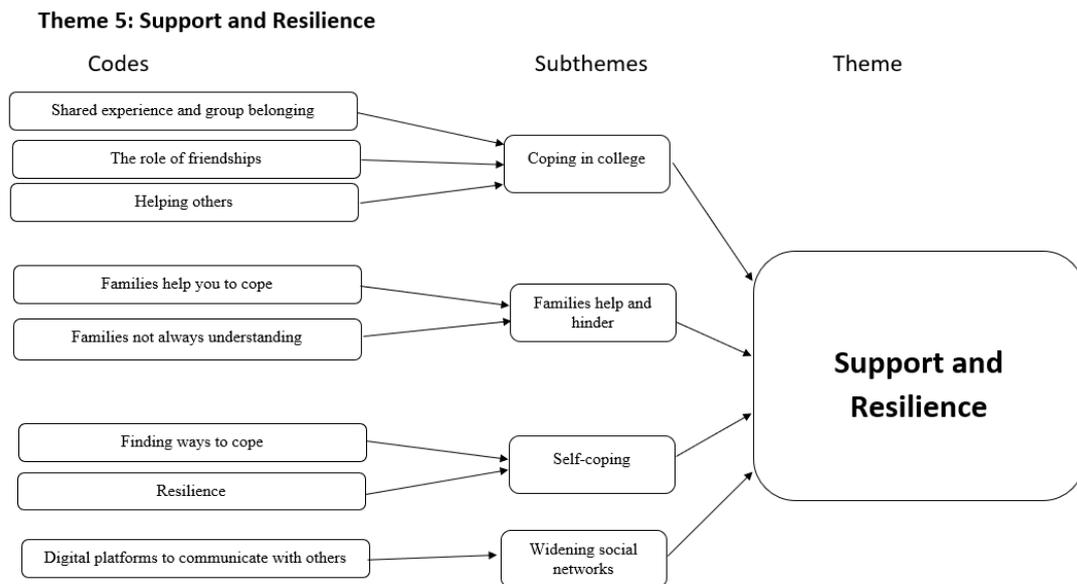
*The only thing it worries me is, em, if they being separated...like they live in different houses* (Sophie, aged 19, group 2, level 4)

As all participants lived at home, this seemed a particularly salient source of stress. However, there was a reluctance to discuss this in detail, and one group was felt that family conflict was “*private*” and suggested that this was not something they shared with others, even if it is a source of stress.

### **3.5 Support and resilience**

Figure 2.5 below illustrates how the subthemes link to the theme Support and Resilience. There was a feeling that participants felt they were understood and accepted in college and that this group belonging played a role in buffering some of the emotional impacts of negative social interactions, creating this sense of support and resilience.

Figure 2.5: Thematic map for Support and resilience



### 3.5.1 Coping in college

Part of this supportive atmosphere appeared to stem from shared negative social experiences in the past and a mutual understanding of the impact of these:

*Like when you're talking with someone your own ages chances are, you're going to have very similar experiences... We all have that shared experience of how much. I'd say, how much of a social mind field [minefield] it [school] was*  
(Jane, aged 18, group 1, level 4)

One participant described how supportive friends had helped him manage his anxiety of meeting new people in college:

*I just stuck to my friend [name] and other friend that was there, that was like, yeah, yeah, I'm fine now* (Ben, aged 19, group 1, level 4)

Most group members cited friendships as helpful and supportive (Figure 2.5). However, negative events of the past did seem to create a cautiousness in developing friendships. This caution was conveyed through an acknowledgement that trusting others and seeking support from friends *sometimes ... maybe take time* (Sophie, aged 19, group 2, level 4). Whilst negative past experiences of others may have created a wariness in trusting people, some previous experiences seemed to promote the benefit of support from friends:

[discussing the role of friends in managing stress] *definitely 'cause I've made a friend when I was little, and he was new to the class. I was kinda nervous to introduce myself to him, but as the years passed we became best friends* (Emily, aged 19, group 3, level 3)

### **3.5.2 Families help and hinder**

The groups acknowledged how stressful family dynamics could be, however, the stress of family dynamics did seem balanced with a sense of support from family members in stressful group activities:

*Yeah cause when I was, I doing my sport like netball I get stressed when my dad isn't there to support me doing my shooting an' all that* (Emily, aged 19, group 3, level 3)

### **3.5.3 Self-coping**

The role of others and their impact on individuals was a major focus when discussing ways to manage social stress. However, an undercurrent of resilience and the ability to self-cope was also evident. In one group, participants described themselves as active

agents of change with a sense of control. For example, one participant commented on using self-talk and space alone when feeling overwhelmed:

*Like you have to say, "it's ok" to say yourself, an' say "it's fine" and have some time to be on my own too (Sophie, aged 19, group 2, level 4)*

Others spoke about finding ways to cope with social stress of family arguments at home but again this self-coping reinforced the feeling of being alone:

*music, it keeps out aw the argument [at home] an' voices all the time (Emily, aged 19, group 3, level 3)*

Overall the group members supported and listened to each other while discussing their experiences of stress, however, some participants offered advice that may serve to exacerbate a stressful situation. For example, in this example, where one participant explained the stress he felt when he was stared at in public:

*Stare back (Chloe aged 19, group 3, level 3)*

*I wish that I can. That's what I do, I make a face at 'em (Thomas, aged 19, group 3, level 3)*

*That makes it worse (Charlotte, aged 19, group 3, level 3)*

### **3.5.4 Widening social networks**

Using digital platforms for communication was debated across the groups as a possible positive way to cope with stress (Figure 2.5). It seemed to provide a mechanism for them

to meet new people with whom they have shared interests, thus increasing their social networks. Some participants highlighted the direct benefits of using online gaming as a platform to widen their social networks:

*one thing is eh, while I do have sort of friends at college, mostly I keep contact through digital platforms... I have a lot of friends in different countries, which is the main way we communicate. I have met some of them, physically; I have met somebody from Denmark in real life (Jane, aged 18, group 1, level 4)*

Online gaming appeared to have a secondary value as a topic for conversations with peers in college. These shared interests seemed to contribute to increased positive social interactions and sense of group belonging in college. Others, however, highlighted that digital platforms are a potential source of social stress that can create risks of cyberbullying that negatively impacts on their psychological wellbeing, as discussed by these two participants:

[cyberbullying] *That's more bad and the worriest thing. It can make you-self... it can make you feel embarrassed (Sophie, aged 19, group 2, level 4)*

*Mmhmm and sometimes it can cause, sometimes it can actually cause mental health conditions (Craig, aged 19, group 2, level 4)*

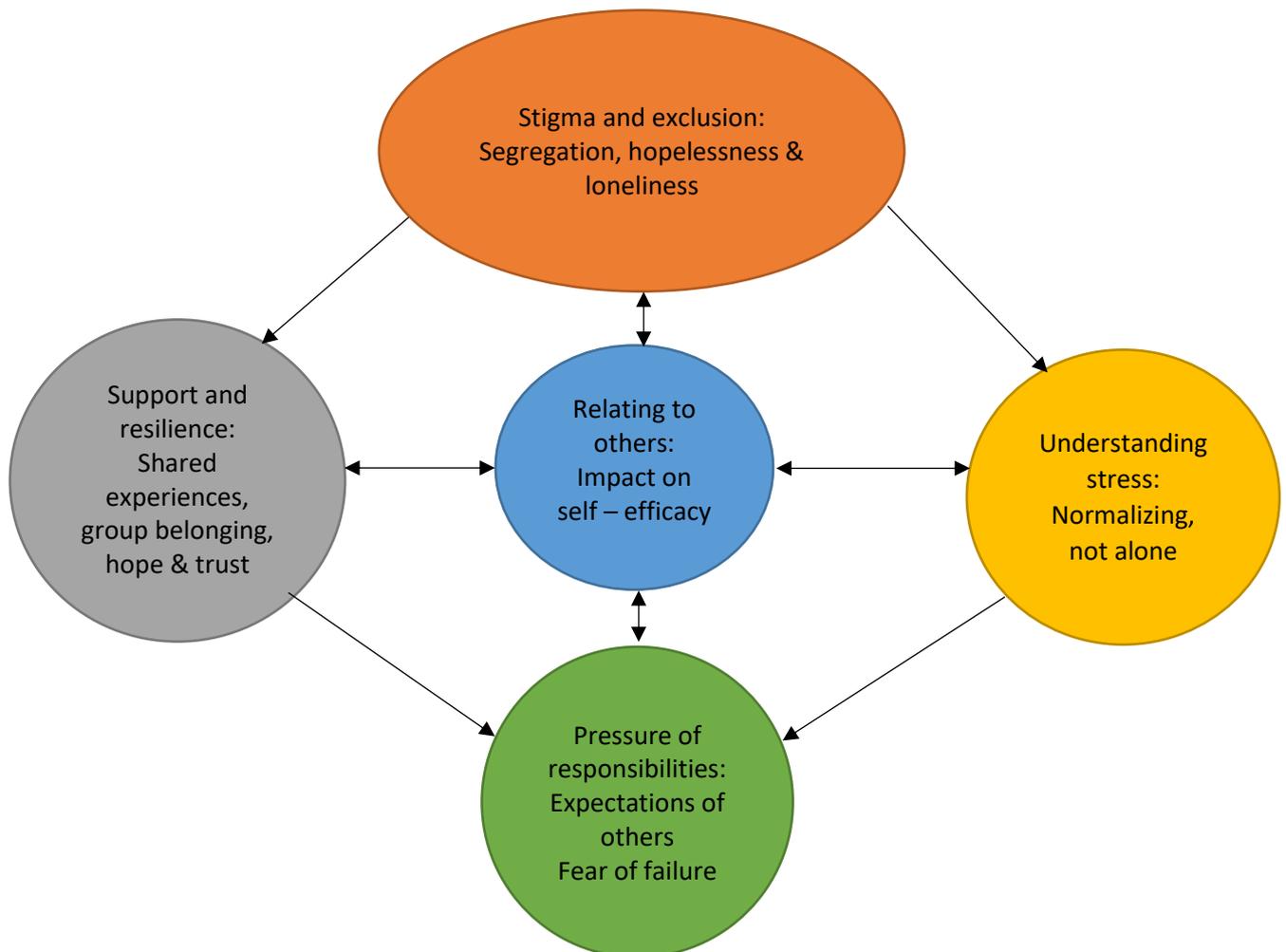
One group went on to discuss how they cope with these social stressors on digital platforms stating *you can just mute the whole chat* (Ben, aged 19, group 1, level 4). This suggests an ability to manage with these digital social stressors and a sense that they

have more control online than with the social stressors they encounter face to face in real life settings.

#### **4 Discussion**

The participants reflected on their sources of social stress, past and present, and communicated their future worries about social stress. Other people they didn't know well seemed to be a source of stress and fear, particularly driven by a fear of how they might be treated and appraised by others. This was counterbalanced by the view that others can be understanding and a source of support to manage social stressors. The key to these supportive relationships seemed to be a development of trust and a feeling of safety and security from belonging to a group with shared experiences. There remained a tension between people's views about college offering the opportunity to develop social confidence and resilience, whilst continuing to contend with persistent feelings of loneliness and hopelessness arising from negative social experiences in the past. The narrative that emerged through the thematic analysis highlights the complex interplay between past experiences, current stressors and worries about social stressors in the future. These relationships are not unidirectional or linear, but multidimensional and dynamic and appear to be changing as these young people transition into adulthood. The overlap in themes shows how closely they inter-relate and are depicted in Figure 2.6 below.

Figure 2.6: Relationships between themes



### *Sources of social stress*

All the groups reported peer pressure, arguments, gossiping and a desire to fit in, as a source of social stress. This is consistent with previous research showing that building relationships and peer status can be a particularly salient source of social stress for young people with intellectual disabilities (e.g. Foley et al., 2012; Jones, 2012). Participants recognised that these concerns may be linked to a sense of social difference and inexperience, particularly compared to their peers. Participants also described similar sources of stress to those for typically developing young people transitioning to adulthood; worries about future prospects and fears of taking on adult responsibilities

(Forte et al., 2011). Students in this study were particularly concerned with the anticipated negative reactions from others if they failed. This fear of social embarrassment seemed to fuel worry about failure. This finding differs slightly from previous studies (e.g. Forte et al., 2011), Participants in level 4 seemed particularly articulate (e.g. Jane, group 1, level 4) therefore, this higher ability may account for the difference in sources of stress and an awareness about the potential social challenges they might face in a work setting, similar to that of their typically developing peers. (Forte et al., 2011). Most of the participants in this study live with their families in relatively deprived areas of Glasgow where there is often a lack financial resources and social supports compared to other, higher socio-demographic, areas. The young people in this study focused on their experiences of social stigma in relation to their education however, the experience of deprivation highlights another potential source of stigma experienced by these young people. Although the impact deprivation was not specifically addressed in the focus groups of this study it is likely to have been a contributing factor to some of the themes that were identified.

#### *Impact of stress*

Reference to past stressors, such as bullying and segregation, seemed to create a fear of speaking up, and feeling de-valued by others, potentially leading to a sense of loneliness, fear of stigma, and a worry about how others perceived them in new social situations. Social comparison to their non-intellectually disabled peers' social skills seemed to reinforce feelings of being ashamed and less able. This low sense of self-efficacy and shame cut across the themes and is consistent with previous research, (Jahoda, Cattermole, Markova, 1988; Banks, & Woolfson, 2008).

#### *Coping with stress*

Participants gave numerous examples of coping strategies; however, this may have reflected what they had learned in class about stress rather than how they coped when faced with real life social stressors. Furthermore, the advice to cope with a real life situation in-vivo in the group (being stared at) appeared to be non-coping strategies (e.g. staring back) that may aggravate a socially stressful situation. This observation perhaps offers some support to Hartley and MacLean's (2005; 2008; 2009) findings about the difficulties people with intellectual disabilities might have found in dealing with stress. This supports the proposal that individuals can perhaps learn coping strategies to manage stress but may require additional support to generalise these strategies to different social situations (Hastings et al., 2004; Rittmannsberger, Kocman, Weber & Lueger-Schuster, 2018).

#### **4.1 Study Limitations**

The focus group created a space for individuals to share their experiences of social stress with peers and thus allowed a normalising of their experiences with their peers that would not have developed through an individual interview. Specifically, the themes of stigma and exclusion suggests that participants benefitted from hearing about other young people's problems and similar experiences in a group setting. In relation to recruitment limitations, education services can often confuse intellectual disability with specific learning difficulties, such as dyslexia, and given the high level of language ability demonstrated in this group this may have been a further limitation of this study. This has been reported as a difficulty in identifying young people with intellectual disabilities in previous studies recruiting from similar colleges (Brougham, Pert, Jahoda, 2020). In future studies, care should be taken to ensure staff understand the nature of intellectual

disabilities. Lastly, this study was designed as a pilot to a larger study and this design should be considered in any interpretation of the results.

#### **4.2 Future Research**

Future research utilising individual interviews could be used to continue to explore the emotional impact of sociodemographic situations and stigma in the community as a source of social stress. Further studies could also examine the impact of deprivation through a comparison of young people living in deprived areas and those living in more affluent areas. This may help to further our understanding of the wider contributing factors to social stress for this population and the impact of these factors on wellbeing; ; this may be particularly pertinent given the association between self-reported stigma and symptoms of anxiety and depression (Ali et al., 2012). Having a diagnosis of autism spectrum disorder can lead to difficulties processing some social signals (Baron-Cohen, 2012) and there is a high co-morbidity (50%) with intellectual disabilities (Baird et al, 2006). Therefore, exploring social stressors specific to this sub-section of young people may warrant additional investigation. Future research could also adapt the methodology of this study, perhaps through individual interviews, to capture salient social stressors of young people with more moderate or severe disabilities. It may also be useful to explore college lecturers' perspectives of how young people with intellectual disabilities cope with social stress. Providing timely social support could have a preventative role in addressing the negative psychological consequences of exposure to social stressors (Cohen & Wills, 1985; Bovier, Chamot, & Perneger, 2004). Further research should continue to trial adapted psychological therapies, such as Compassion Focused Therapy, that could focus on managing the impact of social stress on self-esteem and feelings of

shame. Emerging research shows support for adaptations, but there is a need to focus on personally salient stressors such as those identified in this study (Brougham et al., 2020).

### **4.3 Conclusions**

Overall this study supports previous research showing the salience of social stress in this population, the impact of social stress on their emotional wellbeing, and the difficulties in managing these social stressors. There was, however, an identification of understanding and resilience, suggesting that this population could benefit from adapted interventions. These may help individuals to develop and maintain positive coping strategies to use throughout adulthood, when faced with continued stressful life events, with the hope that these strategies could reduce the negative impact of stigma and social stressors and decrease the risk of mental health difficulties.

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## APPENDIX ONE – SYSTEMATIC REVIEW

### Appendix 1.1 Journal Author Guidelines

Extract of author Guidelines JARID (Full guidelines available at:

<https://onlinelibrary.wiley.com/page/journal/14683148/homepage/forauthors.html#manuscript>)

The terms “learning disabilities” and “learning difficulties”, though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term “learning disabilities or difficulties” where this refers to a specific learning disability/disorder– such as a specific learning difficulty in reading, written expression or mathematics. **If “learning disabilities” or “learning difficulties” are used, authors must not use an abbreviation.**

#### Main Text File

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

- i. Title, abstract and key words;
- ii. Main text;
- iii. References;
- iv. Tables (each table complete with title and footnotes);
- v. Figure legends;
- vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

#### Abstract

All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study.

#### Keywords

Please provide up to six Keywords to aid indexing.

#### References

References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. For more information about APA referencing style, please refer to the [APA FAQ](#). Note that for journal articles, issue

numbers are not included unless each issue in the volume begins with page one, and a DOI should be provided for all references where available.

*Journal article*

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486.  
doi:10.1176/appi.ajp.159.3.483

*Book*

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

*Internet Document*

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from <http://www.youtube.com/watch?v=Vja83KLQXZs>

**Tables**

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and \*, \*\*, \*\*\* should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

**Figure Legends**

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

## Appendix 1.2 Search terms by database

CINAHL (N = **305**)PSYCHInfo (N= **1,440**)MEDLINE (N =**837**)EMBASE (N= **1426**)ERIC (N= **471**)**TOTAL = 4,479****Source: CINAHL**

Interface: EBSCOhost

Database coverage dates: 1990 to date

Search date: 28/10/2020

Retrieved records: 305

Limits: Published Date; Language: English, Human

## Search Strategy:

Subject Headings SC– (No Social Comparison subject heading)

Selected – (MH "Social Adjustment")

Authors Headings SC – (social\* N1 (identit\* OR interaction\* OR perception\* OR accept\* OR approv\* OR conform\* OR adjust\* OR understand\* OR compar\*))

Subject Headings ID – (MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Learning Disorders") OR (MH "Mental Retardation, X-Linked") OR (MH "Down Syndrome")

Author Headings ID – ((learning or intellectual\*) N2 disab\*) OR (mental\* N2 retard\*) OR (down\* syndrome)

S7 S3 AND S6

Limiters - Published Date:

19900101-20201231;

English Language; Human

305

Expanders - Apply

equivalent subjects

Search modes -

Boolean/Phrase

S6	S4 OR S5	Expanders - Apply equivalent subjects	True
			S6
		Search modes - Boolean/Phrase	34,323
S5	TI (((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome)) AND AB (((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome))	Expanders - Apply equivalent subjects	True
			S5
		Search modes - Boolean/Phrase	10,283
S4	(MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Learning Disorders") OR (MH "Mental Retardation, X-Linked") OR (MH "Down Syndrome")	Expanders - Apply equivalent subjects	True
			S4
		Search modes - Boolean/Phrase	33,110
S3	S1 OR S2	Expanders - Apply equivalent subjects	True
			S3
		Search modes - Boolean/Phrase	17,566
S2	TI ( (social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR conform* OR adjust* OR understand* OR compar* ) ) OR AB ( (social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR conform* OR adjust* OR understand* OR compar* ) )	Expanders - Apply equivalent subjects	True
			S2
		Search modes - Boolean/Phrase	14,171
S1	(MH "Social Adjustment")	Expanders - Apply equivalent subjects	True
			S1
		Search modes - Boolean/Phrase	3,838

**Source: PsychInfo**

Interface: EBSCOhost

Database coverage dates: 1990 to date

Search date: 28/10/2020

Retrieved records: 1,440

Limits: Publication Year: 1990-2020; English; Human

## Search strategy:

Subject headings SC – (((DE "Social Comparison") OR (DE "Social Perception")) OR (DE "Social Interaction")) OR (DE "Social Approval")

Author terms SC- (social\* N1 (identit\* OR interaction\* OR perception\* OR accept\* OR approv\* OR conform\* OR adjust\* OR understand\* OR compar\*))

Subject Headings ID – ((DE "Intellectual Development Disorder" OR DE "Down's Syndrome") OR (DE "Learning Disabilities")) OR (DE "Learning Disorders")

Author terms ID – (((learning or intellectual\*) N2 disab\*) OR (mental\* N2 retard\*) OR (down\* syndrome))

S7	S3 AND S6	Limiters - Publication Year: 1,440 1990-2020; English; Population Group: Human Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	<input type="text" value="True"/> <input type="text" value="S6"/> 85,900
S5	TI (((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome)) OR AB (((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	<input type="text" value="True"/> <input type="text" value="S5"/> 66,652
S4	((DE "Intellectual Development Disorder" OR DE "Down's Syndrome") OR (DE "Learning Disabilities")) OR (DE "Learning Disorders")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	69,001
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	<input type="text" value="True"/> <input type="text" value="S3"/> 119,369
S2	TI ( social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR conform* OR adjust* OR understand* OR compar*) ) OR AB ( social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	<input type="text" value="True"/> <input type="text" value="S2"/> 72,850

	conform* OR adjust* OR understand* OR compar* )		
S1	((((DE "Social Comparison") OR (DE "Social Perception")) OR (DE "Social Status")) OR (DE "Social Interaction")) OR (DE "Social Approval")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	<input type="text" value="False"/> <input type="text" value="S1"/> 63,979

### Source: MEDLINE In-Process & Other Non-Indexed Citations and Ovid MEDLINE

Interface: OvidSP

Database coverage dates: 1990 to present

Search date: 28/10/2020

Retrieved records: 837

Limits: English language and yr="1990 -Current") NOT animals

Search Strategy:

Subject headings SC – (No Social Comparison subject heading) Social Perception/ Self Concept/

Author terms SC- (social\* adj1 (identit\* or interaction\* or perception\* or accept\* or approv\* or conform\* or adjust\* or understand\* or compar\*)).ti,ab.

Subject Headings ID – learning disorders/ or intellectual disability/ or down syndrome/ or mental retardation, x-linked/

Author terms ID – (((learning or intellectual\*) adj2 disab\*) or mental\* adj2 retard\*) or down\* syndrome).ti,ab.

1	Social Perception/	22392
2	Self Concept/	55098
3	(social* adj1 (identit* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or compar*)).ti,ab.	24273
4	1 or 2 or 3	95850
5	learning disorders/ or intellectual disability/ or down syndrome/ or mental retardation, x-linked/	89554
6	(((((learning or intellectual*) adj2 disab*) or mental*) adj2 retard*) or down* syndrome).ti,ab.	49421
7	5 or 6	106342
8	4 and 7	1552
9	limit 8 to (english language and yr="1990 -Current")	893
10	limit 9 to animals	56
11	9 not 10	<b>837</b>

### Source: Embase 1990-Present, updated daily

Interface: OvidSP

Database coverage dates: 1990 to present

Search date: 28/10/2020

Retrieved records: 1426

Limits: English language and yr="1990 -Current"), NOT - animals and animal studies, conference abstract status

Search Strategy:

Subject headings SC – (No Social Comparison subject heading) social interaction/  
(Queried social attitudes/ but too vague and broad term as defined by Scope note.)

Author terms SC- (social\* adj1 (identit\* or interaction\* or perception\* or accept\* or  
approv\* or conform\* or adjust\* or understand\* or compar\*)).ti,ab.

Subject Headings ID –mental deficiency/ learning disorder/

Author terms ID – (((learning or intellectual\*) adj2 disab\*) or (mental\* adj2 retard\*) or  
down\* syndrome).ti,ab.

1	social attitude/ or social interaction/	52310
2	(social* adj1 (identit* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or compar*)).ti,ab.	32113
3	1 or 2	71197
4	mental deficiency/	29337
5	learning disorder/	22918
6	(((learning or intellectual*) adj2 disab*) or (mental* adj2 retard*) or down* syndrome).ti,ab.	72923
7	4 or 5 or 6	100087
8	3 and 7	1920
9	limit 8 to (english language and yr="1990 -Current")	1824
10	limit 9 to (animals and animal studies)	139
11	limit 9 to conference abstract status	264
12	10 or 11	398
13	9 not 12	1426

### Source: ERIC

Interface: EBSCOhost

Database coverage dates: 1990 to date

Search date: 28/10/2020

Retrieved records: 471

Limits: Language: English

Search strategy:

Subject Headings SC– No Social Comparison subject heading

Selected – DE "Social Differences" OR DE "Social Adjustment

Authors Headings SC – TI ( social\* N1 (identit\* OR interaction\* OR perception\* OR  
accept\* OR approv\* OR conform\* OR adjust\* OR understand\* OR compar\* ) ) OR AB  
( social\* N1 (identit\* OR interaction\* OR perception\* OR accept\* OR approv\* OR  
conform\* OR adjust\* OR understand\* OR compar\* ) )

Subject Headings ID – (((DE "Intellectual Disability") AND (DE "Mild Intellectual Disability" OR DE "Moderate Intellectual Disability" OR DE "Severe Intellectual Disability"))) OR (DE "Learning Disabilities")) OR (DE "Down Syndrome")  
 Author Headings ID – (((DE "Intellectual Disability") AND (DE "Mild Intellectual Disability" OR DE "Moderate Intellectual Disability" OR DE "Severe Intellectual Disability"))) OR (DE "Learning Disabilities")) OR (DE "Down Syndrome")

S14	S12 AND S13	Limiters - Date Published: 19900101-20201231; Language: English Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S14 471
S13	S9 OR S11	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S13 37,388
S12	S8 OR S10	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S12 19,519
S11	TI ( ((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome) ) OR AB ( ((learning or intellectual*) N2 disab*) OR (mental* N2 retard*) OR (down* syndrome) )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S11 32,599
S10	TI ( social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR conform* OR adjust* OR understand* OR compar*) ) OR AB ( social* N1 (identit* OR interaction* OR perception* OR accept* OR approv* OR conform* OR adjust* OR understand* OR compar*) )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S10 14,810
S9	(((DE "Intellectual Disability") AND (DE "Mild Intellectual Disability" OR DE "Moderate Intellectual Disability" OR DE "Severe Intellectual Disability"))) OR (DE "Learning Disabilities")) OR (DE "Down Syndrome")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S9 19,650
S8	DE "Social Differences" OR DE "Social Adjustment"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	True S8 5,638

## Appendix 1.3 Quality Checklist and extract of guidance

***Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QATCCS) the National Heart, Lung and Blood Institute (NHLBI).***

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Rating (Good, Fair, or Poor)
Rater #1 initials:
Rater #2 initials:
Additional Comments (If POOR, please state why):

\*CD, cannot determine; NA, not applicable; NR, not reported

### **Guidance for Assessing the Quality of Observational Cohort and Cross-Sectional Studies (examples and cohort information removed)**

The guidance document below is organized by question number from the tool for quality assessment of observational cohort and cross-sectional studies.

#### **Question 1. Research question**

Did the authors describe their goal in conducting this research? Is it easy to understand what they were looking to find? This issue is important for any scientific paper of any type. Higher quality scientific research explicitly defines a research question.

#### **Questions 2 and 3. Study population**

Did the authors describe the group of people from which the study participants were selected or recruited, using demographics, location, and time period? If you were to conduct this study again, would you know who to recruit, from where, and from what time period? Is the cohort population free of the outcomes of interest at the time they were recruited?

In cohort studies, it is crucial that the population at baseline is free of the outcome of interest. For example, the nurses' population above would be an appropriate group in which to study incident coronary disease. This information is usually found either in descriptions of population recruitment, definitions of variables, or inclusion/exclusion criteria.

You may need to look at prior papers on methods in order to make the assessment for this question. Those papers are usually in the reference list.

If fewer than 50% of eligible persons participated in the study, then there is concern that the study population does not adequately represent the target population. This increases the risk of bias.

**Question 4. Groups recruited from the same population and uniform eligibility criteria**

Were the inclusion and exclusion criteria developed prior to recruitment or selection of the study population? Were the same underlying criteria used for all of the subjects involved? This issue is related to the description of the study population, above, and you may find the information for both of these questions in the same section of the paper.

Most cohort studies begin with the selection of the cohort; participants in this cohort are then measured or evaluated to determine their exposure status. However, some cohort studies may recruit or select exposed participants in a different time or place than unexposed participants, especially retrospective cohort studies—which is when data are obtained from the past (retrospectively), but the analysis examines exposures prior to outcomes.

**Question 5. Sample size justification**

Did the authors present their reasons for selecting or recruiting the number of people included or analyzed? Do they note or discuss the statistical power of the study? This question is about whether or not the study had enough participants to detect an association if one truly existed.

However, observational cohort studies often do not report anything about power or sample sizes because the analyses are exploratory in nature. In this case, the answer would be "no." This is not a "fatal flaw." It just may indicate that attention was not paid to whether the study was sufficiently sized to answer a prespecified question—i.e., it may have been an exploratory, hypothesis-generating study.

**Question 6. Exposure assessed prior to outcome measurement**

This question is important because, in order to determine whether an exposure causes an outcome, the exposure must come before the outcome.

Sometimes cross-sectional studies are conducted (or cross-sectional analyses of cohort-study data), where the exposures and outcomes are measured during the same timeframe. As a result, cross-sectional analyses provide weaker evidence than regular cohort studies regarding a potential causal relationship between exposures and outcomes. For cross-sectional analyses, the answer to Question 6 should be "no."

**Question 7. Sufficient timeframe to see an effect**

Did the study allow enough time for a sufficient number of outcomes to occur or be observed, or enough time for an exposure to have a biological effect on an outcome? In the examples given above, if clinical depression has a biological effect on increasing risk for CVD, such an effect may take years. In the other example, if higher dietary sodium increases BP, a short timeframe may be sufficient to assess its association with BP, but a longer timeframe would be needed to examine its association with heart attacks.

The issue of timeframe is important to enable meaningful analysis of the relationships between exposures and outcomes to be conducted. This often requires at least several years, especially when looking at health outcomes, but it depends on the research question and outcomes being examined.

Cross-sectional analyses allow no time to see an effect, since the exposures and outcomes are assessed at the same time, so those would get a "no" response.

### **Question 8. Different levels of the exposure of interest**

If the exposure can be defined as a range (examples: drug dosage, amount of physical activity, amount of sodium consumed), were multiple categories of that exposure assessed? (for example, for drugs: not on the medication, on a low dose, medium dose, high dose; for dietary sodium, higher than average U.S. consumption, lower than recommended consumption, between the two). Sometimes discrete categories of exposure are not used, but instead exposures are measured as continuous variables (for example, mg/day of dietary sodium or BP values).

If there are only two possible exposures (yes/no), then this question should be given an "NA," and it should not count negatively towards the quality rating.

### **Question 9. Exposure measures and assessment**

Were the exposure measures defined in detail? Were the tools or methods used to measure exposure accurate and reliable—for example, have they been validated or are they objective? This issue is important as it influences confidence in the reported exposures. When exposures are measured with less accuracy or validity, it is harder to see an association between exposure and outcome even if one exists. Also as important is whether the exposures were assessed in the same manner within groups and between groups; if not, bias may result.

### **Question 10. Repeated exposure assessment**

Was the exposure for each person measured more than once during the course of the study period? Multiple measurements with the same result increase our confidence that the exposure status was correctly classified. Also, multiple measurements enable investigators to look at changes in exposure over time, for example, people who ate high dietary sodium throughout the followup period, compared to those who started out high then reduced their intake, compared to those who ate low sodium throughout. Once again, this may not be applicable in all cases. In many older studies, exposure was measured only at baseline. However, multiple exposure measurements do result in a stronger study design.

### **Question 11. Outcome measures**

Were the outcomes defined in detail? Were the tools or methods for measuring outcomes accurate and reliable—for example, have they been validated or are they objective? This issue is important because it influences confidence in the validity of study results. Also important is whether the outcomes were assessed in the same manner within groups and between groups.

### **Question 12. Blinding of outcome assessors**

Blinding means that outcome assessors did not know whether the participant was exposed or unexposed. It is also sometimes called "masking." The objective is to look for evidence in the article that the person(s) assessing the outcome(s) for the study (for example, examining medical records to determine the outcomes that occurred in the exposed and

comparison groups) is masked to the exposure status of the participant. Sometimes the person measuring the exposure is the same person conducting the outcome assessment. In this case, the outcome assessor would most likely not be blinded to exposure status because they also took measurements of exposures. If so, make a note of that in the comments section.

If blinding was not possible, which is sometimes the case, mark "NA" and explain the potential for bias.

### **Question 13. Followup rate**

Higher overall followup rates are always better than lower followup rates, even though higher rates are expected in shorter studies, whereas lower overall followup rates are often seen in studies of longer duration. Usually, an acceptable overall followup rate is considered 80 percent or more of participants whose exposures were measured at baseline. However, this is just a general guideline. For example, a 6-month cohort study examining the relationship between dietary sodium intake and BP level may have over 90 percent followup, but a 20-year cohort study examining effects of sodium intake on stroke may have only a 65 percent followup rate.

### **Question 14. Statistical analyses**

Were key potential confounding variables measured and adjusted for, such as by statistical adjustment for baseline differences? Logistic regression or other regression methods are often used to account for the influence of variables not of interest.

Appendix 1.4 Quality rating of included studies

	Quality rating for each question														Quality Rating
	Criteria: Yes/No/Other (Cannot Determine (CD), Not Reported (NR), Not Applicable (NA))														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Cooney et al., 2006	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	No	Fair
Crabtree et al., 2001	Yes	Yes	CD	No	No	No	No	NA	No	No	Yes	NA	NA	No	Poor
Dagnan et al, 1999	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
Dagnan et al, 2004	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
McGillivray et al., 2007	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
MacMahon et al., 2008	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	No	Fair
O'Bryne et al., 2017	Yes	Yes	Yes	Yes	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
Paterson et al., 2012	Yes	Yes	Yes	Yes	Yes	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
Szivos, 1991, UK	Yes	Yes	No	No	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair
Szivos-Bach, 1993	Yes	Yes	No	No	No	No	No	NA	Yes	No	Yes	NA	NA	Yes	Fair

## **APPENDIX TWO – MAJOR RESEARCH PROJECT**

### Appendix 2.1 Original study Major Research Proposal

#### **Major Research Project Proposal**

**Title: Social stressors in people with Intellectual Disabilities: Using Compassionate Imagery**

**University Supervisor: Professor Andrew Jahoda**

**Field Supervisor: Dr Carol Pert**

#### **Abstract**

People with intellectual disabilities (ID) report similar common life stressors as the general population, however they have been found to rate social stressors as having the highest negative impact on their wellbeing. Compassion Focused Therapy (CFT) has been found to increase social connectedness in the general population and may be beneficial for helping people with ID develop adaptive coping strategies for social stressors however there is limited existing research. One component of CFT uses imagery techniques and may be less accessible to people with ID due to the cognitive demands of this task.

Building on a small number of recent studies this study aims to investigate using CFI for people with ID for a personally salient social stressor. A secondary aim is to explore associations between self-compassion and social comparison.

This exploratory study will recruit a group of college students, with and without ID. Each group will complete self-report measures (adapted where necessary) on anxiety, self-compassion and social comparison. An adapted imagery technique from CFT will be used and personally salient social stressors will be generated for participants to apply their compassionate image to. The research aims to expand on current evidence in adapting and applying CFT for people with ID and evaluating its utility.

#### **Introduction**

Emerging research suggests that common daily stressors (e.g. relationship difficulties, work stressors, health worries) can have a negative impact on psychological wellbeing (Asselmann, Wittchen, Lieb, Hofler & Beesdo-Baum, 2016; D'Angelo & Wierzbicki, 2003; McIntosh, Gillanders, & Rodgers, 2010; Hutchinson & Williams, 2007). The impact of these stressors appear to change across the lifespan with the highest negative impact, such as depressive symptoms, being found in young adults and adolescents (Goodyer,

2001; Sim, 2000; D'Angelo & Wierzbicki, 2003; Zimmer-Gembeck & Skinner, 2008; Low et al., 2012). This may not be surprising as leaving school and transitioning to adulthood is a key stressor for young people where they can experience increased independence in less structured and supportive academic environments such as colleges and further education. In these environments' individuals receive less support with social tasks, such as developing friendships and relationships, than during childhood and adolescence (Forte, Jahoda, & Dagnan, 2011). This can be particularly challenging for young people with intellectual disabilities (people with ID) who can developmentally struggle with skills required for social and emotional understanding (Foley et al., 2012; Jones, 2012; Thirion-Marissiaux & Nader-Grosbois, 2008) and show a larger proportion of social worries than their peers in further education (Forte et al, 2011). The difference in the nature of stressors was explored by Bramston and colleagues (1999) who found students without ID reported negative social events (e.g. bullying, death and arguments) as their most stressful situations and, in addition, students with ID rated other interpersonal situations (e.g. teasing and being interrupted) as very stressful. They also found that students with ID rated social stressors as having the highest negative impact on their wellbeing. More recently Kavale & Mostert (2004) also found that people with ID reported increased stress in further education; particularly in relation to social competence, social communication, building relationships and peer status. This is of particular relevance to address as recent figures show 1,029 (4.4%) of adults who are known to have a learning disability were enrolled in further education in Scotland in 2018 (SCLD, Learning Disability Statistics Scotland, 2018).

Social worries seem to be a salient source of stress for people with ID in general with findings showing adults with ID also consistently report interpersonal relationships and social situations (e.g. arguments, being interrupted and confrontation) as the most common life stressors they experience (Hartley & McLean, 2004; 2009; Lunsby & Brampton, 2006). Individuals therefore appear to find social situations stressful across the lifespan suggesting a possible area for intervention in young adults to provide coping strategies for individuals to manage the negative impact of these stressors.

Making negative social comparisons to others can also have a negative impact on psychological wellbeing and young people in the general population have been found to make more negative social comparisons than adults (Suls and Mullen, 1982; Callan, Kim & Matthew 2015). Whilst it is unclear if young people with ID make more negative comparisons than young people without ID, research suggests that adults with ID engage in negative social comparisons with others; increasing their feelings of shame, depression and low self-esteem (Ali et al., 2012; Paterson et al., 2012; Dagnan, & Sandhu, 1999). Overall, the high risk of making negative social comparisons with others and experiencing distress from common social stressors may be particularly important in further education due to the focus on increasing social competence and independence.

There may be a number of factors which contribute to an increased tendency for people with ID to make negative social comparisons and to find social situations stressful. Firstly, people with ID have been found to have reduced access to social networks, which are key protective factors for psychological difficulties (Wiener & Schneider 2002;

Brackenridge & McKenzie, 2005; Lafferty, 2008; Heiman, 2001), and they experience high levels of marginalisation and stigmatisation in society (Annison, 2000). Furthermore, people with ID have been found to have limited exposure to positive coping strategies and have difficulties developing and maintaining strategies for managing stressors (Hartley & MacLean, 2005; 2008; Hastings et al., 2004; Rittmannsberger, Kocman, Weber & Lueger-Schuster, 2018). Lastly, people with ID have been found to lack belief in their ability to cope (Jahoda, Cattermole, & Markova, 1988).

Compassion Focussed Therapy (CFT) is a psychological intervention that explicitly focuses on reducing distress from interpersonal difficulties and improving affect regulation to cope with stressors. Compassion Focused Therapy (CFT) is based on attachment theory, Buddhist teaching, and the social, evolutionary and neuropsychological models of affect regulation (Gilbert, 2005; 2009; 2014) and focuses on three affect regulation systems; threat, drive, and soothing (see Gilbert, 2009 for overview). CFT theory proposes that distress is driven by the over-activation of the 'threat system' and under activation of the 'soothing system' and posits that increasing the ability to soothe can help regulate responses to perceived stressors. CFT techniques focus on improving awareness of compassion for self and others to improve physiological wellbeing and increase successful navigation of the social world (Gilbert, 2014; 2019). In general and student populations, increasing compassion for self and others has been shown to reduce stress associated with interpersonal difficulties and increase social connectedness (e.g. Gilbert & Proctor, 2006; Pace, Macbeth & Gumley 2012; Neely, Schallert, Mohammed, Roberts & Chen, 2009; Leaviss, & Uttley, 2014). Self-compassion has also been found to be a unique predictor of negative social comparison (Neff, Hseih, & Dejithirat, 2005). This raises a potential mechanistic question about whether improving the capacity to self-soothe with CFT may buffer against the impact of negative social stressors and negative social comparisons by people with ID.

There is emerging interest in adapting CFT for people with ID. Three published studies have recently looked at CFT in people with ID. Cooper & Frearson (2017) adapted CFT in a single case study, Hardiman and colleagues (2018) delivered individual CFT to 3 participants, and Clapton and colleagues (2016; 2017) used a mixed method approach with 6 participants to examine the feasibility and acceptability of group CFT. Initial findings suggest that developing compassion can help to regulate levels of shame and distress, reduce unfavourable social comparisons (Clapton, Williams, Griffith & Jones, 2017), possibly reduce levels of anxiety, increase compassionate attitudes, increase common humanity, and increase the ability to use compassionate coping techniques (Hardiman et al., 2018). Although these studies had small samples sizes, they provide initial evidence that CFT can be adapted for people with ID. However, the initial pre and post group intervention measures did not show significant changes in self-compassion scores or psychological distress scores (Clapton et al., 2017).

Understanding treatment mechanisms is a key issue, particularly in homogeneous groups (Lorenzo- Lucaces, Gern & De Rubeis, 2015). It is therefore pertinent to further evaluate the core components of CFT for adaptation and utility for people with ID. Clapton and colleagues highlighted concern regarding whether or not people with ID could fully understand and apply each component of CFT as delivered for their group,

particularly for the cognitively demanding tasks such as imagery tasks (Clapton et al., 2017).

Compassion Focused Imagery (CFI) is one of the core therapeutic components of CFT. CFI involves the use of personally salient imagery to help the person self-soothe in response to a stressor. The evidence of CFI in the general population seems to suggest a single session for students can stimulate self-soothing and increase feelings of social connectedness (Rockliff, Gilbert, McEwan, Lightman, & Glover, 2008). CFI has also been investigated for people with psychosis and was found to increase participants' feelings of happiness and reassurance but did not improve negative self-relating, negative affect, or paranoia (Ascone, Sundag, Schlier & Lincoln, 2017). Furthermore in individuals with brain injury a CFI intervention was found to make no significant change (Campbell, Gallagher, McLeod, O'Neill & McMillan, 2017; O'Neill & McMillan, 2012). This suggests a mixed picture and, whilst a brief CFI exercise would not be expected to create lasting change, it warrants further exploration as a key technique in CFT. This may be particularly relevant in people with ID as there is mixed evidence regarding this populations capacity to cognitively engage in imagery tasks (Roskos-Ewoldsen et al., 2006). A recent study offers preliminary support that people with ID may be able to utilise CFI (Brougham, 2018). It was found that students with ID can, with scaffolding, generate a compassionate image and apply it to hypothetical vignettes of difficult scenarios. However, imagining a hypothetical scenario places increased cognitive demand on participants cognitive processing. There is also a lack of face validity as it is not clear if the hypothetical vignettes elicited the personally salient threat responses that CFT is designed to address (Gilbert, 2014; Brougham, 2018).

The current study aims to further explore the utility of CFI to foster the ability to self-soothe for people with ID. The study will be exploratory and aim to identify personally salient social stressors to apply a compassionate image to. It is hoped this will help identify any issues, any necessary modifications, and reduce the risk of future investment in larger scale efficacy studies of a full CFT protocol without first understanding possible difficulties with engagement in cognitively demanding tasks.

### **Aims and hypotheses**

The study proposes to explore the use of an adapted 'Compassionate Image' exercise for college students with ID. The study will explore participants ability to a use a Compassionate image to self soothe when imagining a personally salient social stressor. In light of the limited literature to date this study will be exploratory and cross-sectional, with a comparative group of non-ID students. The study will consist of two parts, investigating:

- A) The types and differences in social stressors reported by the ID and non-ID participants
- B) The difference between ID and non-ID participants in their self-reported ability to generate and use their compassionate image to self-soothe for a personally salient social stressor (yes/no)?

In addition it is hypothesised that:

- 1) The ID group will have significantly higher levels of anxiety, as measured by the Glasgow Anxiety Scale (GAS), compared the non-ID group
- 2) The ID group will have significantly higher levels of negative social comparison, as measured by the Social Comparison Scale (SCS-SF), compared to the non-ID group.
- 3) There will be a negative correlation within both groups between social comparison (SCS-SF) and self-compassion (Adapted Social Comparison Scale)

### **Design**

This exploratory study will utilise a cross-sectional design. A between-subjects design will be used to explore social stressors and identify any differences between the two groups in their self-reported ability to use the compassionate image.

A between-subjects design will be utilised for differences in levels of anxiety and social comparison. A within-subjects quantitative design will be used to explore associations between self-compassion and social comparison.

### **Plan of Investigation**

#### ***Participants***

Two non-clinical groups will be recruited; one group of young adults with intellectual disabilities and a comparison group of typically developing young adults. Participants will be recruited from further education colleges in the Glasgow area. This approach has been used by previous Doctorate in Clinical Psychology trainees and contacts within the colleges have been established. Where possible groups will be matched in terms of age, gender and as closely as possible for socio-economic status.

#### ***Inclusion Criteria***

- Participants must be able to give informed consent
- Participants must have sufficient expressive and receptive language in order to be able to describe the desired characteristics in a 'compassionate image', in addition to being able to describe stressful situations.

#### ***Exclusion criteria***

- Individuals who are currently receiving treatment for mental health difficulties (e.g. psychosis, anxiety or depression) that could prevent them from engaging in the study tasks and serve as a possible confounding factor.
- Individuals with significant physical or sensory impairments that would interfere with their ability to take part in the tasks and engage with the materials.
- Individuals who have a diagnosis of a social communication disorder, such as Autism Spectrum Disorder (ASD), will be excluded. This is due to differences in social responding within this group (World Health Organisation, 2010) which would serve as a confounding factor.

#### ***Recruitment***

The researcher will initially make contact with college staff to discuss the research and to identify classes/groups that could take part. To ascertain whether or not participants have sufficient receptive and expressive language, staff will be supported to apply the following items from the Adaptive Behaviour Scale (ABS-RC:2) (Nihira, Leland & Lambert, 1993): Talks to others about sports, family, group activities, Sometimes uses complex sentences containing 'because', 'but', Answers simple questions such as 'What is your name?' or 'What are you doing?'. The researcher will meet with groups of students, who have sufficient receptive and expressive language, at the college to explain the study and provide a study information sheet (easy read). Students will be provided with a reply sheet and contact number for the researcher. They will be given time to review the information sheets and asked to reply if they are interested. Students will be reminded that they are under no pressure to participate and that withdrawal at any time would not impact on any college related activity. Individual contact will not occur until the individual has indicated interest in participation by phone or return slip. Students who express an interest will be then contacted by the researcher to arrange an individual face to face meeting in a private room within their college; where study information will be reiterated, and written consent will be obtained (easy read). Before verbal and written informed consent is sought participants will be asked to explain their understanding of their role in the research. At all points of contact participants will be asked if they remain happy to proceed with participation.

### ***Measures and experimental tasks***

The measures and tasks that will be used are listed below in the order in which they will be administered:

- 1) **Demographic information:** A background information sheet will be used to collect information on the participants' age, gender, socio-economic status, educational status and postcode. The postcode of each participant will be used to generate the Scottish Index of Multiple Deprivation (SIMD) quintile in order to gain an idea of their level of deprivation (Scottish Government, 2016). The SIMD index is comprised of seven factors, which contribute to overall deprivation: Income, Employment, Education, Health, Access to services, Crime, and Housing. It provides a range from 1 (most deprived) to 5 (least deprived).
- 2) **Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID; Mindham & Espie, 2003).** The GAS-ID is 27 item self-rating questionnaires, used to measure levels of anxiety for individuals with ID. The GAS-ID has good test-retest reliability ( $r=0.95$ ) and internal consistency ( $\alpha = 0.96$ ). The GAS-ID will be used in order to control for this as a factor in the analysis.
- 3) **Short form of the self-compassion scale (SCS-SF; Raes, Pommier, Neff & Van Gucht, 2011)** This scale is a shortened 12-item version of the original 26-item Self-Compassion Scale designed to assess an individual's self-compassion across three components: self-kindness, common humanity, and mindfulness. This provides an overall self-compassion score. No compassion measures have currently been validated for people with ID, however Clapton (2016) adapted the SCS-SF for use with adults with ID and the researcher will approach Clapton for permission to use the adapted version in this study.

- 4) **The adapted Social Comparison Scale (Dagnan & Sandhu, 1999).** This scale was adapted for people with ID from the Social Comparison Scale (Allan & Gilbert, 1995). It examines how people evaluate themselves through comparisons with others, across the domains of rank and achievement, social attractiveness, and group belonging. Lower scores indicate low rank self-perceptions. The adapted scale has demonstrated a similar psychometric structure to the original scale (Dagnan & Sandhu, 1999), and reasonable Cronbach's alphas ( $\alpha = 0.56$  to  $0.76$ ) for this population (Dagnan & Sandhu, 1999; Paterson et al., 2012).
- 5) **Social Stressors rank task to elicit social threat**  
This task will be developed specifically for this study based on a similar procedure from the ID literature on worries (Forte et al., 2011). A focus group will be employed to identify salient social stressors for this population (see below). Following content analysis the themes from the focus group will be used to generate a selection of social stressors. These will be presented to each participant verbally and visually. The participants will be asked to place the pictures on either a mat that has 'yes' written on it that represents 'yes, this is a stressor for me' or on a mat that had 'no' written on it that represents 'no, this is not a stressor for me'. Participants will be asked if they had any social stressors that have not been presented and if so, they can add them to the 'yes' pile. Pictures will be presented in a randomised order to avoid order effects. The participants will be shown a picture of four boxes, each of which gradually decreased in size from the box before it. Participants will be asked to pick their four biggest stressors from their 'yes' pile and rank them in order of the most to the least stressful. The most salient social stressor identified by each participant will be given a score of 4, the second most salient will be given a score of 3 and so on.
- 6) **The Compassionate Image Exercise (Gilbert, 2007; adapted by Brougham 2018)**  
Participants will be introduced to the CFT model and the concept of self-soothing. The adapted 'Kind helper' exercise will be used with both groups of participants. This exercise will ask participants to think about their ideal compassionate other. This will be unique to each individual. They will be asked to think of a person or animal who embodies the characteristics of warmth, non-judgement, wisdom, and empathy. Throughout this exercise the participants will be reassured that there are no right or wrong answers. If individuals are not able to generate a 'Compassionate Image' in the exercise, then they will not be required to continue with the task. Following the task, participants will be asked if they have been able to generate a compassionate image. Participants will then be asked to imagine themselves in their top social stressor scenario (identified in previous task) and asked to use their compassionate image in order to self-soothe any threat response from the social stressor.
- 7) **Wechsler Abbreviated Scale of Intelligence - Second Edition (two-subset form) WASI-II** (Pearson Corporation, 2011). The WASI-II (two-subtest form) [provides an estimate of general cognitive ability](#). It has good validity (0.87) and reliability

(0.88-0.92). The researcher will use this measure in order to confirm that the participants meet the inclusion criteria. It will be administered at the end of the study as the IQ test has a pre-determined set of right and wrong questions. This is contrary to the flow and spirit of the main research tasks which aim to obtain self-report information. Therefore, starting with the IQ might inhibit participants from responding freely.

## **Procedure**

### ***Focus Groups***

Current literature and measures of types and severity of social stressors in young people and people with ID will guide the development of a semi-structured interview for the focus groups (Lakey, Tardiff, & Drew, 1994; Bramston et al., 1999; Hartley & MacLean, 2005; Lunsky & Benson, 2001; Lunsky & Bramston, 2006; Hartly & McLeans, 2009). The aim of the group is to stimulate discussion and allow participants to provide information on their experience of social stressors. There will be two focus groups (one for people with ID and one for those without ID) to explore whether the social stressors reported in the literature resonate with both groups of participants. The aim is to generate relevant and personally applicable social stressors for participants to which they can apply their compassionate image. Participants in the focus group will not be excluded from the main study. Focus groups will last for approximately 45 minutes. These focus groups will be recorded via Dictaphone (with prior consent) and subject to content analysis. This data will be used to generate the list of social stressors for use in the main study.

### ***Pilot***

A pilot study will be conducted with a small number of individuals (N=2 per group) before recruiting participants for the main study. The pilot stage will help to establish the following:

- Ensure that the social stressors task is engaging and meaningful to both groups. As a way of gauging if the social stressors evoke a threat response, the researcher will ask the participant to state how they are feeling within the imagined situation.
- Establish how long it takes to administer the tasks (it is currently estimated that all the study measures and experimental tasks will be carried out over two sessions).
- Establish if any changes need to be made to the administration of the measures e.g. account for the change in language and changes/standardisation across rating scales

### ***Main Study***

Participants will undertake two 1:1 sessions, lasting approximately 60 minutes each, within the college(s). Participants will complete all measures and tasks followed by the Wechsler Abbreviated Scale of Intelligence (2 Subset) (Pearson Corporation, 2011). During both meetings time will be spent building rapport with participants and they will be reminded that they can withdraw, and that there are no 'right' or 'wrong' answers for the self-report measures.

**Data analysis**

The qualitative data from the focus group will be explored using content analysis (Strauss, 1987). This will allow the qualitative data from the focus group to be grouped into categories that represent the topic areas of stressors. This will form the basis for the “salient social stressors” task in the main study. Salient social stressors will be ranked by participants in the main study. Frequencies of the types of social stressors generated by both groups will be presented and differences between the groups examined.

To examine differences between the two group’s anxiety and social comparison scores independent t-tests will be used. Within-group associations between the social comparison and self-compassion scores for both the ID and non-ID group will also be explored with Pearson’s correlation. If the data does not meet parametric assumptions, the appropriate non-parametric tests will be used instead.

**Justification of sample size**

This is an exploratory study into the social stressors and use of CFI for people with ID. There are no previous control studies of CFT in people with ID and current published studies have a maximum of 6 participants, using qualitative or mixed method design. Previous Doctorate in Clinical Psychology projects, with similar designs and participants, have successfully recruited sample sizes of between 39-41 participants within the project timeframe (Simpson, 2013; Brougham, 2017). This project will therefore aim to recruit 40 participants (20 with ID and 20 without ID). There will be an additional 4 participants for the pilot (2 in each group) who will not be included in the main study.

**Health and Safety Issues***Participant safety issues*

All individuals will be required to have sufficient receptive and expressive verbal ability in order to describe characteristics of a Compassionate Image. Due to their level of receptive and expressive verbal ability, the researcher will explain the study, and the participant is likely to be able to consent. The researcher will ensure that the participants have fully consented (written consent required) prior to taking part in the study. It will be particularly important to ensure that participants fully understand what the study involves, while maintaining their rights and dignity (Lacono, 2006), this will be considered and addressed in detail.

During the pilot stage, participants will be asked to rate their distress when completing the stressor task. If it is rated too high, this will be reviewed by the researcher and supervisor prior to the main study. Worries have been addressed successfully in other studies (Forte et al., 2011) without causing the participant high levels of distress. Individuals have also noted that they found this process engaging and meaningful. However, if individuals do find the Social Stressors task too distressing then it will be stopped. The researcher in the first instance will obtain the participant’s consent to contact someone who can support them such as a lecturer, their GP or support worker. Participants will be given a full debrief. If they remain distressed, the researcher will support them, and provide numbers for Breathing Space/Samaritans/other relevant charities should the individual require additional support.

*Researcher safety issues*

The researcher will collect the data within a confidential room at a college, which they will become familiar with. The study will take place during staff working hours to ensure that someone will be located nearby to the researcher, and who will be aware of when the researcher is meeting with participants.

**Ethical Issues**

The researcher will apply for ethical approval through the University of Glasgow Ethics Committee. Only the consent forms will hold patient identifiable information, and these will be stored securely within the university building.

**Timetable**

Recruitment is anticipated to begin in autumn 2019. Data analysis and write-up will be completed by summer 2020 with Viva scheduled for September 2020. Further write up for publication will be in late 2020.

**Costs**

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	N/A	N/A
Postage	N/A	N/A
Photocopying and Laser Printing ( <b>includes cost of white paper</b> )	Black and white print 1 sheet = 5 pence 560 prints in total at 5p each (including: background information sheets, consent forms, measures, and experiments, excluding the WASI)	Subtotal: £28.00
Equipment and Software	N/A	N/A
Measures	WASI recording forms (Pearson website.)	Pack 25 x 2 = 50. Subtotal: £163.20 (including VAT)
Miscellaneous	N/A	
<b>TOTAL</b>	<b>£ 191.20</b>	

**Possible Applications**

The research aims to expand current evidence in adapting and applying CFT for people with ID. Previous research has highlighted a need to understand the mechanisms and

utility of CFT techniques initially before evaluating whole protocol approaches. It is hoped that evaluating the ability of individuals with ID to engage in this approach for personal salient stressors will increase the relevance for application in clinical settings where individuals would be applying CFI to their own difficulties.

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**Appendices for proposal:**

**Proposal Appendix B: Research Equipment cost form**

**Research Equipment cost form  
RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES**

**Trainee:**

**Year of Course: 2nd Year**

**Intake Year: 2017**

Please refer to latest stationary costs list (available from student support team)

**Appendix A: Health and Safety Form**

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW  
DOCTORATE IN CLINICAL PSYCHOLOGY  
HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Evaluating Compassionate Mind Training for social stressors in people with Intellectual Disabilities
2. Trainee	Susan Mason-Roberts
3. University Supervisor	Professor Andrew Jahoda
4. Other Supervisor(s)	Field Supervisor: Dr C [REDACTED]
5. Local Lead Clinician	
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	Experimental group – Individuals with an Intellectual Disability over 18 years old Control group – Individuals without an Intellectual Disability over 18 years old
7. Procedures to be applied (eg, questionnaire, interview, etc)	All participants will complete the following: <ul style="list-style-type: none"> <li>• Background information sheet (including demographic information)</li> <li>• Glasgow anxiety scale</li> <li>• Social Comparison Scale</li> <li>• Compassionate image exercise (to be adapted for this study)</li> <li>• Wechsler Abbreviated Scale of intelligence 2nd edition (WASI-II)</li> </ul>
8. Setting (where will procedures be carried out?) i) Details of all settings	College of participants Follow up phone call to be completed from University of Glasgow

Version 29/09/2015 (draft)

ii) Are home visits involved	N
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**WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW  
DOCTORATE IN CLINICAL PSYCHOLOGY  
HEALTH AND SAFETY FOR RESEARCHERS**

<p>9. Potential Risk Factors Considered (for researcher and participant safety):</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<p>Potential for violence and aggression from participants. Potential for participants to become fatigued during the course of the study.</p> <p>Remind participants of right to withdraw at any time during study.</p> <p>Ensure confidentiality of session through appropriate privacy in environments sessions conducted in.</p>
<p>10. 10. Actions to minimise risk (refer to 9)</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<p>Participants energy levels will be observed and monitored by the primary researcher</p> <p>If there is doubt regarding level of risk, I will discuss with their University supervisor and/or a senior member of the clinical team that have responsibility for management of the patient.</p> <p>Inform college or visits and sign in according to their security procedures.</p> <p>Inform university or field supervisor of dates and times of each session</p>

Trainee signature: San Man Date: 25/1/19  
 University supervisor signature: [Signature] Date: 25/1/19

Version 29/09/2015 (draft)

**Appendix B: Research Equipment cost form**

**Research Equipment cost form  
RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES**

**Trainee:**



**Year of Course: 2nd Year**

**Intake Year: 2017**

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
------	-----------------------------	---

Stationary	N/A	Subtotal: N/A
Postage	N/A	Subtotal: N/A
Photocopying and Laser Printing ( <b>includes cost of white paper</b> )	Black and white print 1 sheet = 5 pence 560 prints in total at 5p each (including: background information sheets, consent forms, measures, and experiments, excluding the WASI)	Subtotal: £28.00
Equipment and Software	N/A	Subtotal: N/A
Measures	WASI forms available from the Pearson website. 46 copies required Manual and materials available to borrow from the department.	Pack of 25 = £81.60 (including VAT) Pack of 25 X 2 from Pearson website = 50. Subtotal: £163.20
Miscellaneous	N/A	Subtotal: N/A
Total	£191.20	

**For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:**

### **Appendix C: Plain English Summary**

#### **Social stressors in people with Intellectual Disabilities: Using Compassionate Imagery**

##### Introduction

Research shows us that young people, particularly those with an intellectual disability (ID), find daily events such as social interactions the most stressful (Kavale & Mostert, 2004) and this can have a negative effect on their wellbeing (Lunsky & Bramston, 2006). Individuals with ID have also been found to make more negative social comparisons than the general population. Compassion Focused Therapy (CFT) is used to help people who find social situations difficult and can help address difficulties in feeling socially

connected and has had some success for people with LD (Hardiman, Willmoth, & Walsh, 2018).

#### Aim

There are currently very few studies to tell us what social situations are most stressful for young people with ID or if CFT can be useful for helping people with ID manage these stressors. It is hoped that this study will explore this, and find ways that CFT might be adapted for young people with ID.

#### Procedure

This research will achieve this by using an adapted exercise from CFT called the 'Compassionate Image'. Participants will be recruited from local colleges Glasgow. The study will compare two groups of participants; a group of young people with ID and a group of young people without ID. Participants will meet with the researcher to complete some self-report questionnaires on self-compassion, social comparison and anxiety. They will then complete some tasks to identify their social stressors and then they will complete the Compassionate Image exercise, which builds an image of a person or object that brings comfort to the person. The participant will then be asked to try to use the compassionate image to help them cope when they imagine themselves in their stressful social situation. They will be asked if they could do this task. The data will then be analysed to compare the data between each group and look for overall associations.

#### Ethics

Participants will be given the opportunity to opt in and given full information on the details of the study. They will be told that they have the right to withdraw at any time and that their details will be made anonymous. The study will not proceed until it has ethical approval from the Glasgow University Ethics Committee.

#### Practical Implications

It is hoped that this research will build on an evidence base to explore adapting CFT for this group of people and help identify how we can help young people with ID manage stressful social situations and negative social comparisons.

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Kavale, K., & Mostert, M. (2004). Social skills interventions for individuals with learning disabilities. *Learning Disability Quarterly*, 27, 31-42.

Lunsky Y, Bramston P. (2006) A preliminary study of perceived stress in adults with intellectual disability according to self-report and informant ratings. *Journal of Intellectual and Developmental Disability*; 31:20–27.

## Appendix D – Glasgow Anxiety Scale for People with Intellectual Disabilities by Mindham & Espie (2003)

Each item scored as: (0) ‘never’; (1) ‘sometimes’; and (2) ‘always’.

Question Score

### Worries

- 1 Do you worry a lot? (...feel worked up/wound up/uptight/up to high doh)
- 2 Do you have lots of thoughts that go round in your head? (...thoughts that you can't stop/come from nowhere)
- 3 Do you worry about your parents/family?
- 4 Do you worry about what will happen in the future? (tailored to the individual; e.g. What will happen if you can't live with your mum anymore?)
- 5 Do you worry that something awful might happen?
- 6 Do you worry if you do not feel well? (...if you feel sick)
- 7 Do you worry when you are doing something new? (...like for the first time)
- 8 Do you worry about what you are doing tomorrow?
- 9 Can you stop worrying? (reverse score)
- 10 Do you worry about death/dying?

### Specific fears

- 11 Do you get scared in the dark? (...think of being in bed with the lights out: Would you be scared?)
- 12 Do you feel scared if you are high up? (...think of being up a high building...)
- 13 Do you feel scared in lifts or escalators? (Would you go in?)
- 14 Are you scared of dogs? (Would you stroke/clap?)
- 15 Are you scared of spiders? (Would you go near?)
- 16 Do you feel scared going to see the doctor or dentist?
- 17 Do you feel scared meeting new people?
- 18 Do you feel scared in busy places? (...like crowds, shopping centre)
- 19 Do you feel scared in wide open spaces? (...nothing round about you)

### Physiological symptoms

- 20 Do you ever feel very hot or sweaty? (...all hot and bothered)
- 21 Does your heart beat faster?
- 22 Do your hands and legs shake?
- 23 Does your stomach ever feel funny, like butterflies?
- 24 Do you ever feel breathless? (...hard to breathe/out of breath)
- 25 Do you feel like you need to go to the toilet more than usual? (...for a ‘pee’)
- 26 Is it difficult to sit still? (...feel you can't sit at peace)
- 27 Do you feel panicky? (...get into a panic/a ‘state’)

## Appendix E - SELF-COMPASSION SCALE–Short Form (SCS–SF) 2

### HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

<b>Almost Never</b>	<b>Sometimes</b>	<b>About half of the time</b>	<b>Quite a lot</b>	<b>Almost always</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

- \_\_\_\_\_ 1. When I get something wrong I feel like I'm no good at anything
- \_\_\_\_\_ 2. I try to be kind to myself about the things I don't like about me
- \_\_\_\_\_ 3. When something happens that upsets me, I try to think carefully and calmly about what has happened
- \_\_\_\_\_ 4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.
- \_\_\_\_\_ 5. When I get things wrong I remind myself that everyone gets things wrong sometimes
- \_\_\_\_\_ 6. When I'm going through a hard time, I try to care of myself
- \_\_\_\_\_ 7. When something upsets me I try to keep my emotions in balance.
- \_\_\_\_\_ 8. When I fail at something that's important to me, I tend to feel like the only one
- \_\_\_\_\_ 9. When I'm feeling down I tend to get stuck on thinking about what is wrong.
- \_\_\_\_\_ 10. When I feel no good/ not good enough in some way, I try to remind myself that everyone feels like they're not good enough sometimes.
- \_\_\_\_\_ 11. I give myself a hard time about the things I'm not good at or don't like about myself
- \_\_\_\_\_ 12. I can't stand/accept the parts of me that I don't like.

**Coding Key:**

Self-Kindness Items: 2, 6

Self-Judgment Items: 11, 12

Common Humanity Items: 5, 10

Isolation Items: 4, 8

Mindfulness Items: 3, 7

Over-identified Items: 1, 9

Subscale scores are computed by calculating the mean of subscale item responses. To compute a total self-compassion score, reverse score the negative subscale items - self-judgment, isolation, and over-identification (i.e., 1 = 5, 2 = 4, 3 = 3, 4 = 2, 5 = 1) - then compute a total mean.

**Appendix F: The adapted Social Comparison Scale (Dagnan & Sandhu, 1999)**

1. When I am with other people I  
generally feel:

worse than  
other people

better than  
other people

---

2. When I am with other people I  
generally feel:

better at  
things

not as good  
at things

---

3. When I am with other people I generally feel:

More friendly

Less friendly

---

4. When I am with other people I generally feel:

more  
shy

less  
shy

---

5. When I am with other people I generally feel:

part of the  
group

on my  
own

---

6. When I am with other people I generally feel:

the same

different

---

**Proposal Appendix G**

**Adapted Compassionate Image task: The Kind Helper record sheet**

1. Would you imagine this to be a person (man or woman), an animal or a cartoon/film character?		
If a person selected...	If an animal selected...	If a fictional character...
<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Man?</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Woman?</div> </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Old?</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Young?</div> </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 30%;">Tall?</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 30%; margin-left: 20px;">Small?</div> </div>	<div style="border: 1px solid black; border-radius: 15px; padding: 10px; margin-bottom: 10px;">                     What kind of animal?  <i>Open first, then ask</i>                      Is the animal from a Farm / Zoo / Home?                 </div> <div style="display: flex; justify-content: space-around; margin-bottom: 10px;"> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Big?</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Small?</div> </div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 80%;">                     What colour of animal?                 </div>	<div style="display: flex; justify-content: space-around; margin-bottom: 10px;"> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Person?</div> <div style="border: 1px solid black; border-radius: 10px; padding: 5px; width: 40%;">Animal?</div> </div> <div style="border: 1px solid black; border-radius: 15px; padding: 10px; margin-top: 10px;">                     If person go to person flowchart                       If animal go to animal flowchart?   <i>May improvise qns on response given</i> </div>
2. Is there anything else that you can tell me about how it looks?		
3. Give it a name? (once it is named X, refer to this throughout the rest of the exercise)		

4. Can you imagine what X's voice is like?	
Quiet ?	Loud?
Soft voice?	Deep voice?
High pitched?	Low pitched?

5. Can you imagine what X would say to you? (open ended)

6. I'll going to say some other phrases and I want you to tell me if you can imagine X saying these to you?	
I care about you	
I'll be here for you no matter what	
You can depend on me	
I understand how you feel	
I'm here to help you	

7. Is there anything else that you want to add about X?

Appendix 2.2 Recruitment progress for original study

Table of recruitment progress for original study

Recruitment for two groups at end point of recruitment March 2020 – Intellectual disabilities group and Non- Intellectual disabilities group:

LD group		Non-LD group	
Focus Groups:	1) 4 participants (completed)  2) 3 participants (completed)  3) 6 participants (completed)	Focus Group:	9 participants (Completed)
Pilot Group: (n = 2)	2 participants  (2 completed session 1)	Pilot Group: (n = 2)	2 participants  (1 completed session 1)
Main Study: (n = 20)	14 participants (consent given to complete after pilot)	Main Study: (n = 20)	30 reply sheets  8 Participants (consent given to complete after pilot)

## Appendix 2.3 Ethical Approval Letter



Dear Professor Andrew Jahoda

**MVLS College Ethics Committee**

**Project Title:** *Social stressors in people with Intellectual Disabilities: Using Compassionate Imagery*  
200190019

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study.

We are happy therefore to approve the project, subject to the following conditions.

- Project end date as stipulated in revised application.
- Data are anonymous with no participant identifiable data.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:  
([http://www.gla.ac.uk/media/media\\_227599\\_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf))
- The research should be carried out only on the sites, and/or groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- For projects requiring the use of an online questionnaire, the University has an Online Surveys account for research. To request access, see the University's application procedure at <https://www.gla.ac.uk/research/strategy/ourpolicies/useofonlinesurveystoolforresearch/>.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Dr Terry Quinn

## Appendix 2.4 Participant Information Sheets

(non-Easy read sheets for all participant written sheets were also provided to give participants choice of information presentation).



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

**Participant Information Sheet (Easy Read) – Focus group**      **Version 6**  
**15/11/2019**

**Study:** Social stressors in people with Intellectual Disabilities: Using  
Compassionate Imagery

**Name of Researchers:** Susan Mason-Roberts (Trainee Clinical Psychologist),  
Professor Andrew Jahoda (Consultant Clinical Psychologist) and Dr Carol Pert  
(Consultant Clinical Psychologist)



Please read this information sheet



You can ask someone to read it with you



You can talk to someone you trust about it



Take time to think about it



You do not have to take part if you do not want to



My name is Susan Mason-Roberts

I am doing research at the University of Glasgow

I have help from my supervisor Professor Andrew Jahoda who is a University Professor and a Consultant Clinical Psychologist and Dr Carol Pert, a clinical psychologist



This study is looking at stressful social situations and ways of coping

I want to find out what social situations young adults at college find stressful and if a short task, called a 'Kind Helper', can help



You are part of a group of people I would like to speak to if you:

- Do or do not have a Learning Disability
- go to college
- Are aged between 16 and 25 years old

I will be looking to speak to about 40 people

If you decide to take part in the study I will ask you if you have a Learning Disability



If you are getting treatment for a mental health condition you will not be able to take part in the study. If you have Severe Sensory Impairment or Dementia, you will not be able to take part in the study.



The study will take place between Autumn 2019 and Summer 2020



If you start the study and want to stop – this is OK  
You do not have to give a reason to stop



If you want to take part, this is what will happen



You are being asked if you would like to take part in a group discussion called a Focus Group.

This will be a group where you will be with other college pupils and we will discuss what social situations you find stressful.



This group will be part of a bigger study and the results of our discussions will be used to form part of the main study.

The group will be in your college. It last about 45 minutes. With your permission I would record what we say on a voice recorder to help me remember the things that you have told me.

You will not be asked to do anything before or after this group meeting.

If you do not want to take part in the focus group you can still take part in the main study.

If you don't want to take part in the main study you can still take part in this focus group discussion.



Nothing bad would happen to you and I will ask you to let us know if anything in the study is upsetting or too hard.



Things you say will be kept private

Unless I am worried about your safety.

I will ask for your GP details and ask you if it is ok for us to contact them if we are worried.



You can say stop at any time if you want to



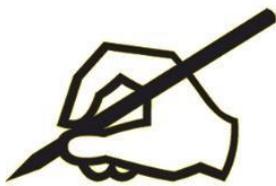
Once the research is finished it will be written up in a report.

Your details will not be in the report and no-one will be able to find out who you are from this report.

Other people will read this report

You can ask for a copy of the report

### Contact Details



If you have any questions you can write to me at:

Susan Mason-Roberts

Trainee Clinical Psychologist.

Mental Health and Wellbeing

1st floor, Administration Building,

Gartnavel Royal Hospital, 1055 Great Western Road

Glasgow ,

G12 0XH



You can email me at:



You can phone me at:

0141 211 3920



### **You can also ask my supervisor questions**

#### **Professor Andrew Jahoda**

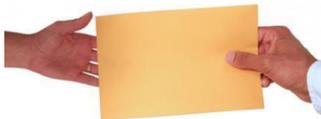
Consultant Clinical Psychologist  
Mental Health & Wellbeing,  
Gartnavel Royal Hospital  
1055 Great Western Road,  
Glasgow,  
G12 0XH

Tel : 0141 211 0607

Email : [Andrew.Jahoda@glasgow.ac.uk](mailto:Andrew.Jahoda@glasgow.ac.uk)

### **If you have concerns and wish to contact an independent person, please contact:**

Professor Hamish McLeod  
DClinPsy Programme Director  
Mental Health and Wellbeing,  
1st Floor Admin Building,  
Gartnavel Royal Hospital,  
G12 0XH



If you are interested

Fill in the reply sheet and pass over to the researcher or to your tutor and I will contact you

## Appendix 2.5 Participant reply sheet



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

**Participant reply sheet (Easy Read)****Version 1****CONTACT DETAILS**

**Title of Study:** Social stressors in people with Intellectual Disabilities: Using Compassionate Imagery

**Researcher:** Susan Mason-Roberts, Trainee Clinical Psychologist



I am interested in finding out more about this study



I consent for my details to be passed to the researcher who will then contact me.

I would like to be contacted by *(tick appropriate response)*:



**Post/letter**



**Email**



**Telephone**

Please provide details of how you would like to be contacted in the space below.



**Address:**

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---

---



**Telephone Number:**

---



Email Address: \_\_\_\_\_

Please circle the answer you agree with:	YES	NO	
	If you want to be contacted by phone are you happy for a message to be left on an answering machine	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix 2.6 Study Consent Form

**Study Consent Form - Easy Read**

**Version 2**

**Study:** Social stressors in people with Intellectual Disabilities: Using Compassionate Imagery

**Name of Researchers:** Susan Mason-Roberts (Trainee Clinical Psychologist), Professor Andrew Jahoda (Consultant Clinical Psychologist) and Dr Carol Pert (Consultant Clinical Psychologist)

Please circle the answer you agree with:	YES	NO	
	<p>Have you read the information sheet?</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>Have you had the chance to ask questions?</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I would like to participate in the research?</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

	<p>I know that I can change my mind or stop at any time</p>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	<p>I agree that to focus group being tape recorded</p>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	<p>I agree to the things I have said being written about without my name being on them</p>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	<p>I agree to the researcher phoning my Doctor if they are worried about me</p>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

<b>Signed by the participant:</b>
<b>Date:</b>
<b>Signed by the appropriate adult (if necessary):</b>
<b>Date:</b>
<b>Signed by the researcher:</b>
<b>Date:</b>

(1 copy for participant; 1 copy for researcher; 1 copy for appropriate adult if signature given)

Appendix 2.7 Background information sheet



**Background Information Sheet**

<b>Participant number</b>	
<b>Gender</b>	<b>Male</b> <input type="checkbox"/> <span style="margin-left: 150px;"><b>Fema</b></span> <input type="checkbox"/>
<b>DOB</b>	
<b>GP details</b>	
<b>Scottish Index of Multiple Deprivation (SIMD)</b>	
<b>Living situation</b>	<b>Living alone</b> <input type="checkbox"/> <b>Living with family</b> <input type="checkbox"/> <b>Living with partner</b> <input type="checkbox"/> <b>Living with a housemate</b> <input type="checkbox"/> <b>Living in a group home</b> <input type="checkbox"/>
<b>College course</b>	
<b>Regular activities/ Hobbies</b>	

<b>Employment?</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Copy of results?</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Group</b>	<b>Case</b> <input type="checkbox"/> <b>Control</b> <input type="checkbox"/>
<b>Initial meeting</b>	<b>Date:</b> <b>Location:</b>
<b>Consent given</b>	<b>Date:</b>
<b>Participation in study</b>	<b>Date:</b> <b>Location:</b>
<b>Results sent</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/> <b>Not applicable</b> <input type="checkbox"/> <b>Date:</b>

## Appendix 2.8 Focus Group Discussion Guide

**FOCUS GROUP: DISCUSSION GUIDE****Facilitator's welcome, introduction and instructions to participants**

**Welcome** and thank you for volunteering to take part in this focus group. We have asked you to join us today as we would really love to hear your views, opinions and thoughts today and we would like everyone here to get a chance to talk and that everyone talks as much, or as little, as they like. We know this may seem like a difficult topic to talk about and we want to let you know that we will treat what you say confidentially.

**Introduction:** This focus group discussion is designed to find out more about what social situations college students find most stressful.

This discussion will take no more than one hour.

**Anonymity:** I will be writing down what you say (with no names of course! This is totally anonymous) but just in case we can't get everything down on paper is it ok if we tape record this session to help me remember what we discuss. This is really to help me write up what was said after today. Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow any of you to be linked to what you say.

What I'll do is begin by covering the ground rules of the group and then ask some general questions to get the discussion going. Please speak up if you disagree with what's being said - we want lots of different ideas and opinions. Can I check that everyone has read the information sheet? (if not go through this before we start)

We would really like to hear from everyone and I would be nice if we can agree to listen to each other and let everyone have a turn at speaking. We may be a tempted to jump in when someone is talking but please wait until they have finished. This is simply a discussion so there are no right or wrong answers and we are just interested in your opinion and views. If anyone feels uncomfortable

or wants to leave the group this is absolutely fine. Has everyone had a chance to read the participant information sheet?

[if agreement, switch on the recorder]

### **Warm up**

- Today we are going to talk about stressful situations. We all experience stressful situations for example meeting new people or sitting tests. I thought I would start by telling you about a recent stressful situation I have been in and how it made me feel.

[INSERT FACILITATORS STRESSFUL SITUATION]

- Stress is a really normal experience and we can have different levels of stress.
- Stress can mean different things to each person – what does the word Stress make everyone think of? [write/draw on flipchart/whiteboard]
- Would anyone feel able to share a recent stressful situation they have encountered or a situation that has been stressful for someone they know?

### **Introductory exercise**

Exercise: I have a number of situations people report as being stressful here on cards can you place the situations in order deciding what you think is most stressful to you. (Testing: What situations do young people think is most stressful?).

**Group Discussion** - If you are comfortable sharing these ... discussion.

### **The list: (to be read out by facilitator and/or written on board)**

- 1 Family (e.g. fights or arguments)
- 2 Relationships (e.g. romantic relationships)
- 3 Friendships (e.g. making friends)
- 4 Bullying (e.g. being bullied by others or a friend being bullied)

- 5 Appearance (e.g. worrying about how you look)
- 6 Meeting new people (e.g. starting a new course or meeting a new student)
- 7 Class discussions (e.g. talking in front of others)
- 8 Staff (e.g. talking to tutors/staff in college)
- 9 Loneliness (e.g. not having people to talk to in college)
- 10 Social gatherings (e.g. going to a party with other students)
- 11 Not being supported (e.g. not having support from others in social situations)
- 12 Getting in trouble at college (e.g. being told off by staff)

### **Guiding questions for discussion**

#### Personal

- What does stress mean to you?
- What do you think are the biggest stresses are in your college?
- How often do you think you get stressed by these situations?

#### Others

- What do you think makes other people stressed at college?
- What do other students tell you they find stressful?

#### Coping

- If a friend or family member was stressed by one of these situations, what would you say to them? What would you recommend them to do?
- How do you cope with these stresses? What helps?
- Do other people do anything that help? If yes – what do they do? If no - what could they do to help?

### **Concluding question**

- Of all the things we've discussed today, what would you say are the most important issues for you?

### **Conclusion**

- Thank you for participating. This has been a very successful discussion
- Thank you all for sharing your thoughts and feelings
- We hope you have found the discussion interesting
- If there is anything you found difficult about this group or are unhappy or wish to complain about any part of this, please contact me or speak to me after we finish
- I would like to remind you that any comments we write about will be anonymous

### **Handout**

- Contact details of facilitator (PIS)

Appendix 2.9 Extract of coding

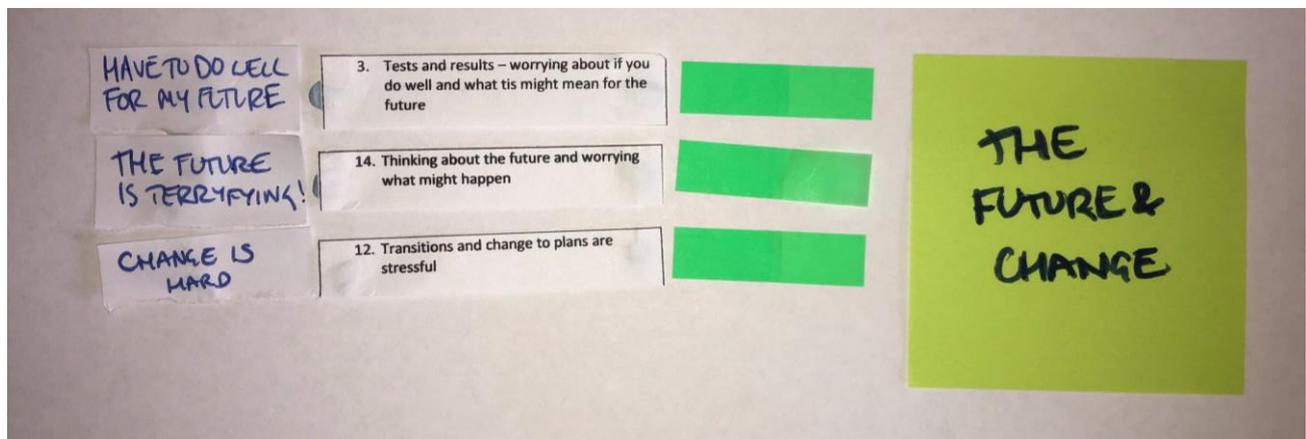
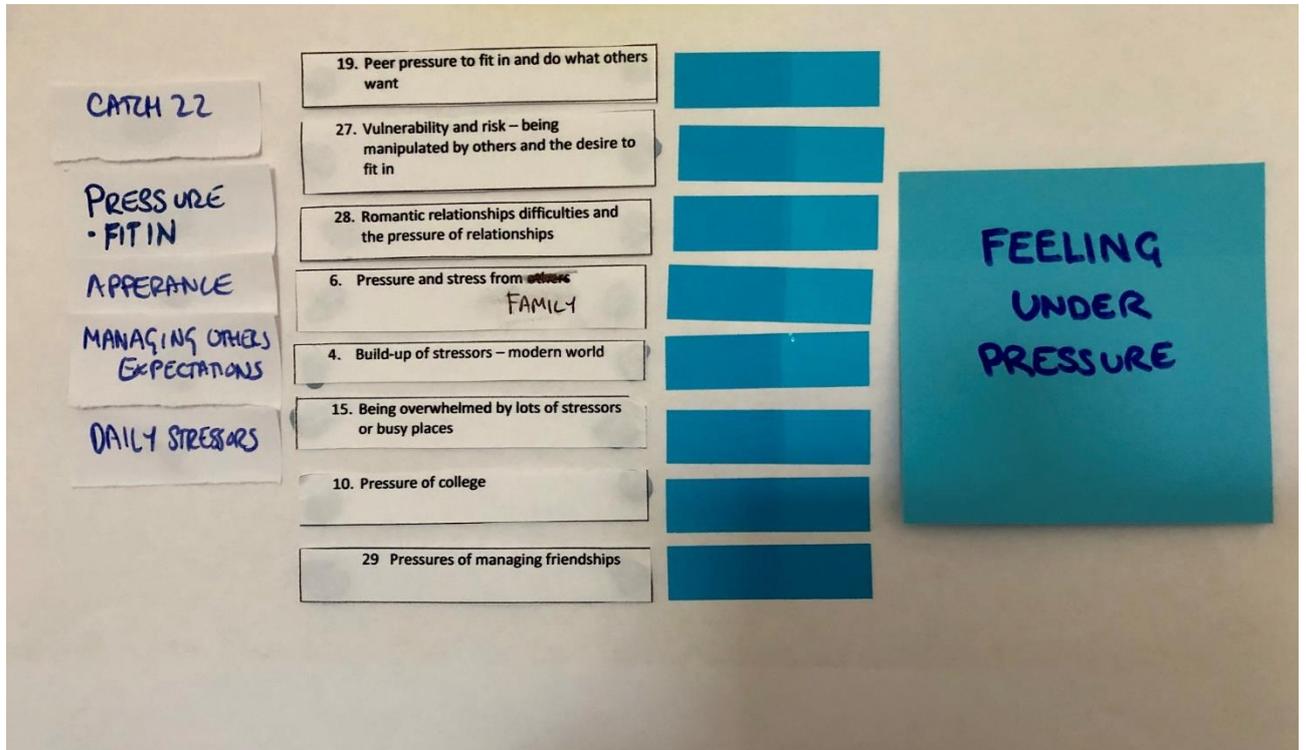
<p>P.3 - <u>yes</u></p> <p>F: and it can make me feel sick</p> <p>P.1 - for me it was just secondary school overall over the years, eh, from like maybe 3<sup>rd</sup> or 4<sup>th</sup> year it kinda just plateaued and then went downhill fast, eh, because I didn't have many friends throughout secondary school aside from people that I knew in primary school</p> <p>F: <u>so</u> friends? do you think friends are important?</p> <p>P.4 - friends are very important, friends can, not always, but they can sometimes relieve some of that stress</p> <p>P.1 - they can help relieve your stress, aye</p> <p>P.4 - Just by talking to them it helps</p> <p>F: mmhmm so friends can be helpful</p> <p>P.1 - and when you don't exactly have an outlet for your frustration, eh, I remember when I was very...when I was very young I was first going into secondary school and I was recently diagnosed with Asperger's Syndrome and, eh, this was because in primary school all my teachers knew me, they knew me well, eh, so they all understood that I probably had Asperger's. I wasn't diagnosed at the time but they all kind of had a hankering. Like, <u>yes</u>, it's probably it. Eh, but they thingmied me to get diagnosed and they, they talked to my parents about getting diagnosed, uh, so that</p>	<p>What causes stress -</p> <p>Memories of secondary school</p> <p>What causes stress -</p> <p>Bad experiences in school - <u>giving presentations</u></p> <p><u>Lack of friends (social support / someone to talk to) makes it harder to cope</u></p> <p>What causes stress -</p>	<p>Past stresses are still relevant (school)</p>	<p><b>SM</b> Susan Mason-Roberts (PGR) Importance of secondary school {CODE 9}</p> <p><b>SM</b> Susan Mason-Roberts (PGR) Not being able to make/maintain friends; importance of friendships {CODE 18}</p> <p><b>SM</b> Susan Mason-Roberts (PGR) importance of friendships - they help relieve stress by talking to them {CODE 18} Talking to others helps {CODE 19}</p> <p><b>SM</b> Susan Mason-Roberts (PGR) Importance of having a way to cope -outlet for frustration {CODE 20}</p> <p><b>SM</b> Susan Mason-Roberts (PGR) importance of secondary school {CODE 9}</p>
<p>the secondary school could be put in any measures necessary to help me if there is any, sort of, stressful situations from transitions. And what ended up happening was I was put into a specialised class, the mosaic room, and it felt really frustrating, being put into the mosaic room because it wasn't, the main problem for me was that I struggled at social situations but the mosaic room filled with all people from disabilities, it was one size fits all and I felt like I was being ignored almost</p> <p>P.4 - <u>pfff</u>, segregation</p>	<p>Bad experiences in school - no friends</p> <p>What helps - having friends, someone to talk to</p> <p>What causes stress - not</p>	<p>Past stresses are still relevant (school)</p>	<p><b>SM</b> Susan Mason-Roberts (PGR) Being segregated {CODE 22} Loss of individual identity - one size fits all. People not listening - being ignored {CODE 21} No sense of belonging or people to relate to - no shared experiences? {CODE 17}</p> <p><b>SM</b> Susan Mason-Roberts (PGR) Being segregated {CODE 22}</p>

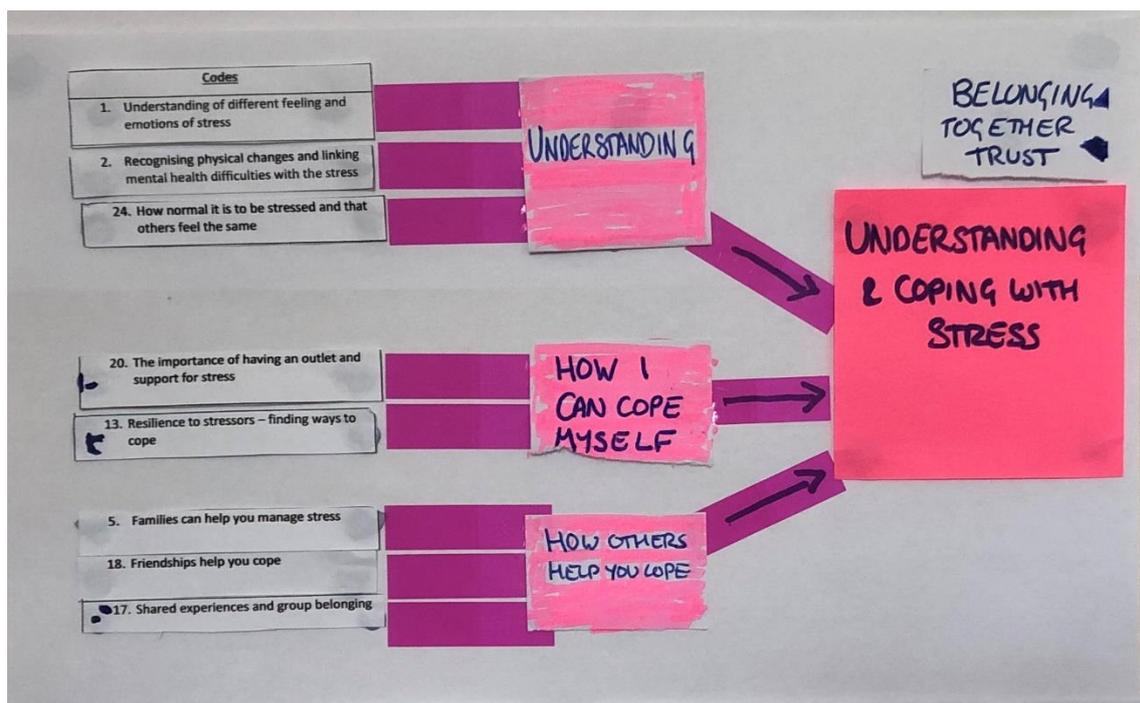
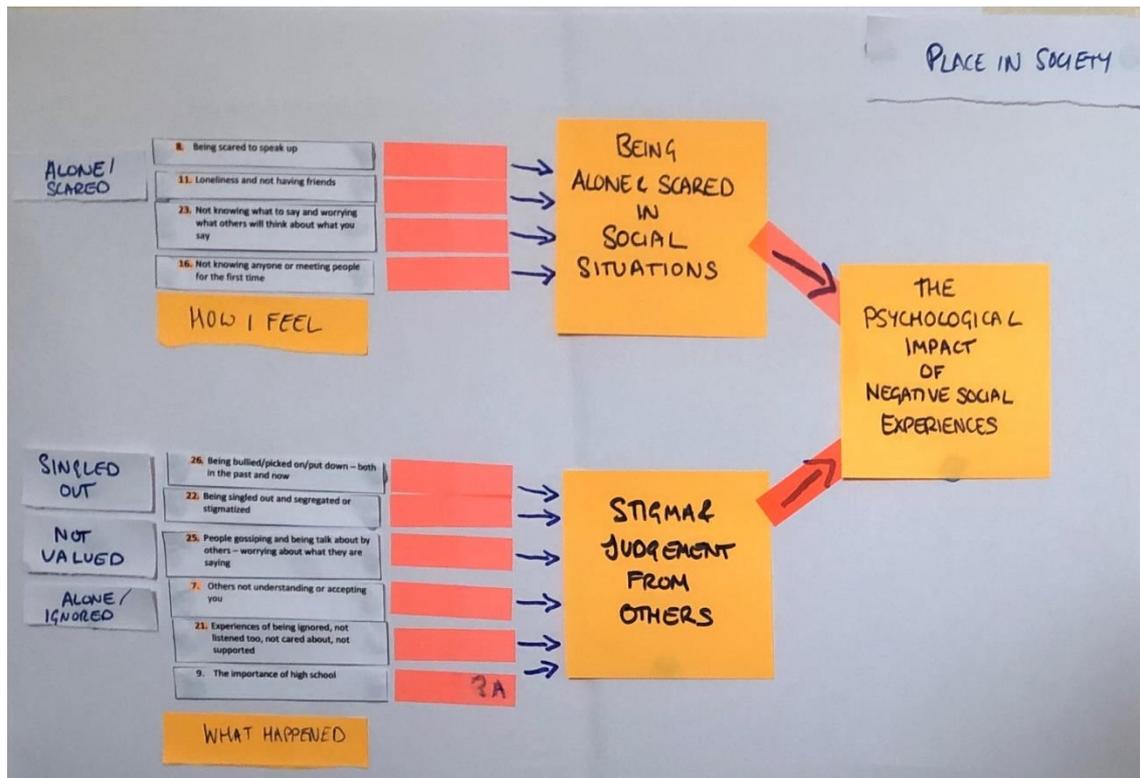
## Appendix 2.10 Extract of Master Coding Document

Code	Quote (Participant number)	Additional comments /observations
1. Understanding stress as an evolutionary and recognising normality of it	<p>P.1: That both people and most animals know</p> <p>P.1 – I'd say branching off of the natural feeling thing it's like an instinctual thing... That animals evolve for survival but nowadays it's just something that's almost just nagging</p> <p>P.1 – and these are perfectly normal reactions to, you know, stressful situations</p> <p>F: mmm, who do you think gets stressed? P.8: everybody F: everybody gets stressed, so it's really normal isn't it P.9: <u>yeh</u></p> <p>P.1. because it starts, because when you see humans are sort of pattern centred creature, like when we notice a pattern</p> <p>P.9: I, I, a gut feeling <u>kinda</u> like</p> <p>P.7: don't like being involved in arguments, it's bad for <u>yeh</u> P.5: I don't think anyone does</p> <p>P.5: because, I think most people would have worried about talking to others, talking in front of others</p> <p>P.5 - most people probably care about their <u>appearance</u> so they do</p> <p>P.1 – and these are perfectly normal reactions to, you know, stressful situations</p>	<p>Understanding of emotional processes and where they came from – that it's an instinct and everyone feels it</p> <p>Language – using different words but connected to the meaning of what it is to be stressed</p> <p>P.5 - Recognising that other people in society feel the same and that they also experience similar stressful events that result in them feeling frustrated and stressed</p> <p>A built in instinct – helpful but makes us feel <u>awfull</u></p>

### Appendix 2.11 First and final thematic maps

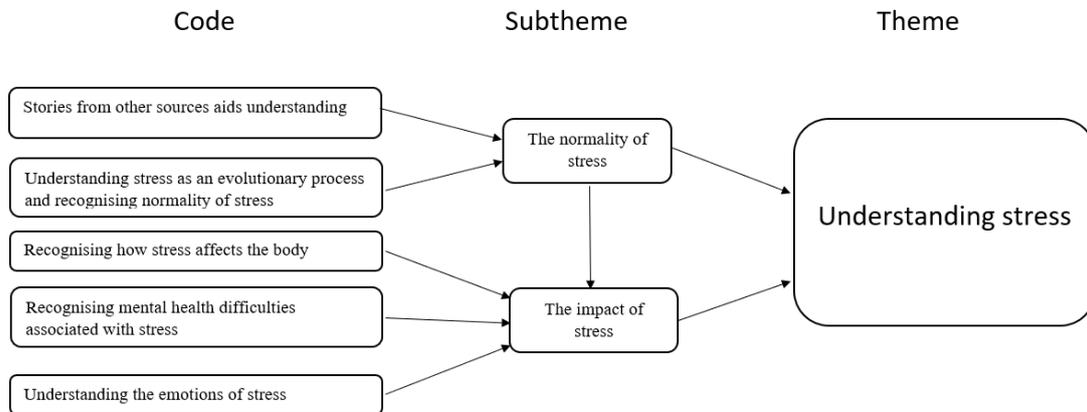
#### First thematic maps



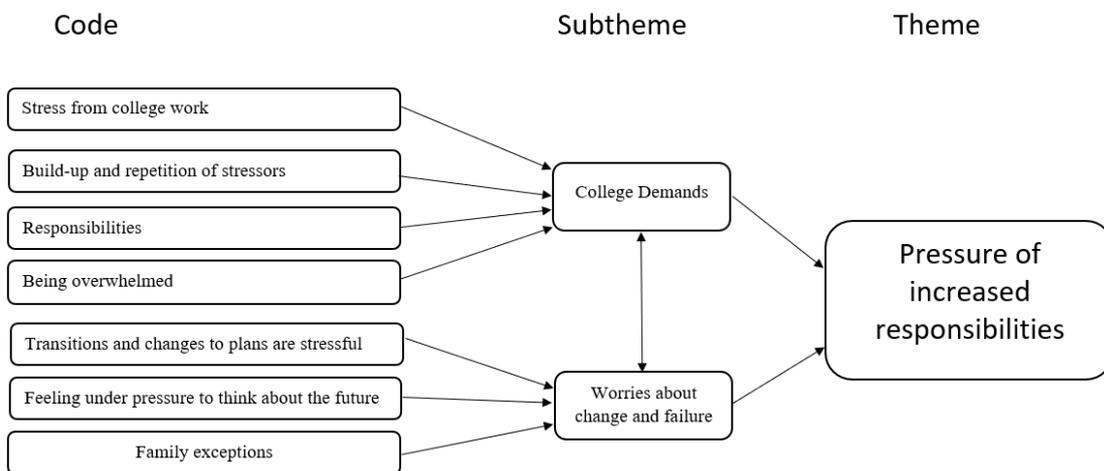


## Final thematic maps

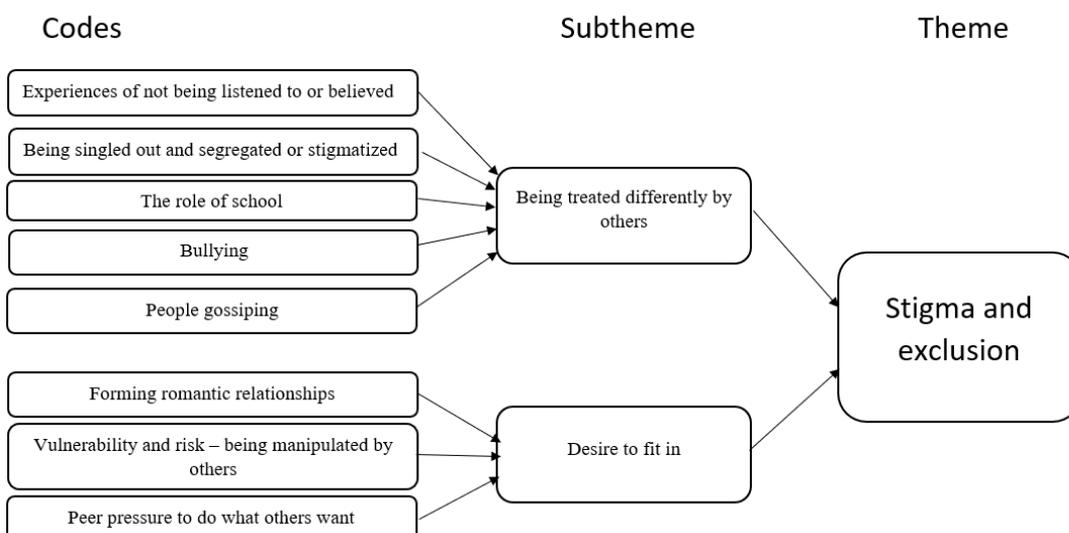
### Theme 1: Understanding stress



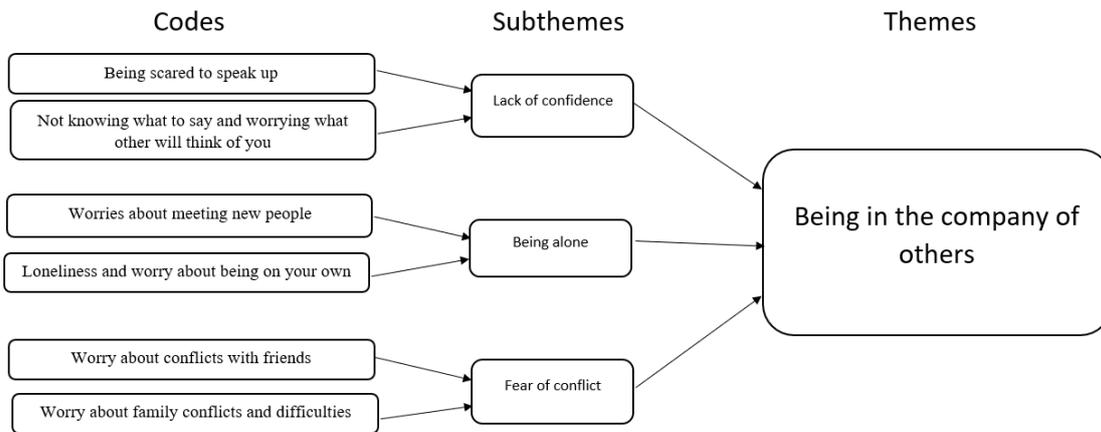
### Theme 2: Pressure of increased responsibilities



### Theme 3: Stigma and exclusion



**Theme 4: Being in the company of others**



**Theme 5: Support and Resilience**

