



University
of Glasgow

Johnson, Maria (2021) *Exploring the development of self and sense of belonging among young people with intellectual disabilities in mainstream school and further education college*. D Clin Psy thesis.

<http://theses.gla.ac.uk/82469/>

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten: Theses

<https://theses.gla.ac.uk/>
research-enlighten@glasgow.ac.uk



Exploring the development of self and sense of belonging among young people with intellectual disabilities in mainstream school and further education college.

Maria Johnson, MA (Hons) MSc

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

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

September 2021

TABLE OF CONTENTS

CONTENTS	PAGE
LIST OF TABLES	4
LIST OF FIGURES	5
FOREWORD	6
ACKNOWLEDGEMENTS	9
 SYSTEMATIC REVIEW.....	 9
ABSTRACT	10
1. INTRODUCTION	11
2. METHODS.....	15
2.1 Search Strategy	15
2.2 Study Selection.....	16
2.3 Data Analysis.....	18
2.4 Quality Appraisal.....	18
3. RESULTS	19
3.1 Quality Rating of Studies	19
3.2 Participant Characteristics	21
3.3 Study Characteristics	30
3.4 Results.....	30
3.4.1 Global Self Concept.....	30
3.4.2 Academic/Cognitive Self-Concept.....	32
3.4.3 Social Perceptions	34
3.4.4 Self-Concept and Importance Ratings	37
4. DISCUSSION.....	38
4.1 Methodological Limitations and Future Research	41
4.2 Implications.....	43
4.3 Conclusions	44
5. REFERENCES	45
 MAJOR RESEARCH PROJECT	 53
PLAIN ENGLISH SUMMARY.....	54
ABSTRACT	56
1. INTRODUCTION	57
2. METHODS.....	62
2.1 Design.....	62
2.2 Participants	62

2.3 Socio-Demographic Questions and Interview	63
2.4 Procedure	64
2.5 Analysis	66
2.6 Ethical Considerations	68
3. RESULTS.....	68
3.1 “They don’t fully understand what my school was like”: Experiences of Stigma and Awareness of Difference.....	70
3.2 “It was great! I felt like I wasn’t left out anymore”: Sense of Belonging ...	73
3.3 “When I go to college, it’s a completely different set of confidence”: Self-Identity Changing Over Time.....	75
3.4 “It’s given me so many benefits”: Transition to College.....	77
3.5 “It’s just a disability... But I rise back”: Desire to Succeed	81
4. DISCUSSION	82
4.1 Study Limitations.....	85
4.2 Implications and Future Research	87
4.3 Conclusion	88
5. REFERENCES	89
APPENDICES	95
APPENDIX ONE: SYSTEMATIC REVIEW.....	95
APPENDIX 1.1 JOURNAL AUTHOR GUIDELINES	95
APPENDIX 1.2 SEARCH TERMS BY DATABASE	98
APPENDIX 1.3 QUALITY RATING TOOL.....	102
APPENDIX TWO: MAJOR RESEARCH PROJECT	105
APPENDIX 2.1 ORIGINAL STUDY MRP PROPOSAL.....	105
APPENDIX 2.2 RESEARCH EQUIPMENT COST FORM	119
APPENDIX 2.3 RESEARCH HEALTH AND SAFETY FORM	120
APPENDIX 2.4 ETHICAL APPROVAL LETTER	122
APPENDIX 2.5 PARTICIPANT INFORMATION SHEET.....	123
APPENDIX 2.6 CONSENT FORM	131
APPENDIX 2.7 INTERVIEW SCHEDULE AND BACKGROUND INFORMATION SHEET	133
APPENDIX 2.8 EXTRACT OF CODING	136
APPENDIX 2.9 EXTRACT OF MASTER CODING DOCUMENT	137
APPENDIX 2.10 INDIVIDUAL PARTICIPANT SCHEMATICS	138
APPENDIX 2.11 FINAL THEMATIC MAPS.....	141

LIST OF TABLES

CHAPTER ONE: SYSTEMATIC REVIEW

TABLE 1 AUTHOR SEARCH TERMS	15
TABLE 2 QUALITY RATINGS	20
TABLE 3 STUDY DESIGN, CHARACTERISTICS, MAIN FINDINGS AND LIMITATIONS	23

CHAPTER TWO: MAJOR RESEARCH PROJECT

TABLE 1 PARTICIPANT CHARACTERISTICS	63
TABLE 2 OUTLINE OF THEMES IDENTIFIED THROUGH ANALYSIS	69

LIST OF FIGURES

CHAPTER ONE: SYSTEMATIC REVIEW

FIGURE 1 FLOW CHART OF SYSTEMATIC SEARCH PROCESS	17
--	----

CHAPTER TWO: MAJOR RESEARCH PROJECT

FIGURE 1 FLOW CHART INDICATING THE RECRUITMENT PROCESSES	65
--	----

FIGURE 2 SCHEMATIC SHOWING RELATIONSHIPS BETWEEN THEMES.....	83
--	----

Foreword

This foreword is included to provide context to this thesis, as the major research project was significantly impacted by the COVID-19 pandemic. The major research project originally aimed to explore the experience of stigma and the perceptions of self and others, by young people with an intellectual disability. The proposed method involved recruiting young people with intellectual disabilities from local colleges. A quasi-experimental design was proposed, and involved a novel Attribution Task used by Deakin et al (2017) to investigate the young people's self-perceptions. This proposal was developed between January 2019 and March 2020, and required face-to-face contact with participants for recruitment and data collection (see appendix 2.1 for proposal). However, due to major disruptions caused by the restrictions put in place to limit the spread of COVID-19, all students were advised to work from home, which involved colleges moving to remote teaching via MS Teams. With the physical distancing restrictions in place, and an inability to meet with participants in person at their home, college or another confidential space to collect data, the original planned project could not proceed.

As a result, I developed a new project to explore a similar research question using a different method, which involved interviewing participants over MS Teams. However, the COVID-19 restrictions negatively impacted on recruitment for this new project, which resulted in a smaller than planned sample size. In total, six colleges were contacted and asked if they could assist with participant recruitment. However only one college was able and willing to help. During conversations with colleges, staff from all colleges emphasised

that they have had to make major adjustments to their work and therefore were understandably less able and willing to help with recruitment for a research study. Furthermore, many colleges expressed reluctance to place additional demands on their students during this time; many of whom were reported to be experiencing increased difficulties with mental health and wellbeing due to the restrictions in place.

Typically, recruitment would usually be carried out face-to-face by giving an initial presentation to relevant classes about the study, or setting up a stall in the college; but this was not possible. Not being able to meet with the researcher prior to the interview, may have led to increased anxiety among potential participants which may have made them more reluctant to volunteer for the study. Additionally, due to the remote delivery of teaching, college lecturers had less contact with their students and could only contact them online. This was a limitation of recruitment because it was more challenging to follow-up with potential participants, as email was the only way of communications. This relied on young people remembering to regularly check their college emails.

Nevertheless, the study was able to proceed despite a smaller than planned sample size. The limitations of this are discussed in the paper.

Acknowledgements

I would first like to thank my supervisor, Prof. Andrew Jahoda, for all of his support and guidance during this project; for making sure I was always “cooking on gas”; and for sharing his knowledge and enthusiasm for research with me.

Thank you, also, to all of the college staff and students who took part in this study. I appreciate you taking the time to help during what was understandably a more difficult college year for you all.

A very special thank you to my husband, Aaron, for all of his love, support, flower deliveries and personal sacrifices throughout my DClínPsy journey – we made it across the finish line of our hardest marathon yet!

I owe a big thank you and lots of gratitude to my parents, who have always supported and encouraged me towards my goals. I also want to thank the best proof-reading team anyone could ask for, David and Noor, and to Rachel for your help with the Review.

Finally, thank you to all of my friends who have been so understanding and supportive over the past three years, particularly Maria, Rachel and Meghan, and thank you to my DClínPsy friends. Clinical training and writing a thesis is tough during the best of times; let alone during multiple lockdowns and a global pandemic. I feel so fortunate to have made friends for life through the DClínPsy, and I’m looking forward to all the celebrations to come.

Chapter One: Systematic Review

What is the impact of attending mainstream school on perception of self in
school learners with Intellectual Disabilities? A Systematic Review and
Narrative Synthesis

Prepared in accordance with the author requirements for Journal of
Applied Research in Intellectual Disabilities (JARID); Appendix 1.1

Abstract

Background: There are many factors which may impact on the self-concept of children with intellectual disabilities. With greater inclusion of children with intellectual disabilities into mainstream education, it is important to understand how these experiences impact on their self-perceptions. This review provides a narrative synthesis on the literature.

Method: A search of relevant electronic databases was completed. Six studies met the inclusion criteria for this review. Each paper's method was rated for quality using the Johanne Briggs Institute quality appraisal tool.

Results: Synthesis of the results highlighted mixed findings for global self-concept and social self-concept scores among children with intellectual disabilities, and lower academic self-concept scores.

Discussion: This review discussed limitations in the existing literature, and implications for education and national policies. Future studies should aim to address methodological weaknesses in order to clarify global and social self-perceptions within this population.

Key words: intellectual disabilities, self-concept, education

Introduction

In the UK, the British Psychological Association (BPS) state three core diagnostic criteria for a diagnosis of intellectual disability. This includes significant impairment across intellectual functioning, adaptive functioning, and with an onset in childhood. Whilst there is variation in how intellectual disabilities are defined internationally, deficits in cognitive and adaptive behaviour which begin in childhood are common features across all definitions (BPS, 2015).

Over recent years in the United Kingdom, there have been key shifts in government policies towards a greater inclusion of people with intellectual disabilities in mainstream environments (Scottish Executive, 2000; UN convention on the rights of the child, 1989). The Standards in Scotland's Schools Act (2000) promoted the inclusion of children with intellectual disabilities in mainstream schools. The rationale behind the change towards a "presumption of mainstream" regarding school placements, was to provide all children with the opportunity to access a good quality education, to feel part of a community, to enhance their emotional wellbeing, and to promote a more inclusive society (Scottish Executive, 2000). However, simply attending a mainstream school does not always equate to feelings of inclusion; there are many factors which contribute to feeling genuinely included in the school community such as, the formation of friendships, receiving the right support and being able to participate in all opportunities of school life (Enable, 2017).

Feeling included at school, and participating in school life, can play a crucial role in the development of identity for children and young people (Verhoeven et

al., 2019). School-aged children's identity, and how they view themselves, can be shaped by many factors including experiences of learning and academia, and peer attitudes towards them (Fields and Enyedy, 2013). Despite a move towards a more equitable school experience for all children, literature suggests there continues to be differences between the developing self-concept scores of students with intellectual disabilities, and typically developing students.

Self-concept can be defined as our knowledge and perceptions of ourselves (Bong and Skaalvik, 2003). It is thought to be a multidimensional phenomenon (Harter and Pike, 1984), that can take into account many different psychological processes, such as: self-recognition, self-evaluations and self-description (Glenn and Cunningham, 2001). Existing research has examined self-concept among populations of children and young people, and found that poor self-concept can have a negative impact on social outcomes (Split et al., 2014) and mental health (Connolly, 1989) in later life. Although much of the existing literature has focused on typically developing populations, self-concept has also been explored among individuals with intellectual disabilities.

However, due to difficulties with measuring self-concept in this population relatively few studies have been conducted (Glenn and Cunningham, 2001).

The research conducted to date suggests key differences between how school-aged children with intellectual disabilities view themselves, compared to typically developing peers. For example, Griffiths (1975) and Cooley and Ayres (1988) report that school-aged children with intellectual disabilities score lower on measures of global self-concept, than typically-developing peers.

Festinger's social comparison theory (Festinger, 1954) explains this difference

through the hypothesis that individuals' self-evaluations are influenced and shaped through comparisons with others. Based on this theory, it was thought that children with intellectual disabilities in mainstream schools may compare themselves negatively with more able class peers, resulting in lower self-concept scores (Crabtree and Rutland, 2001). This view was supported by the results of a recent systematic review, which suggested children with intellectual disabilities self-concept was influenced by their social comparisons with peers (Mason-Roberts, 2020). In addition, Glenn and Cunningham, (2001) have pointed to an age discrepancy between the self-concept scores of children with intellectual disabilities; with older children reporting more negative self-concept scores than younger children. They suggested that the ability to self-evaluate by comparing oneself with peers, is a cognitive ability which develops later among children with intellectual disabilities. Although a lack of ability to make comparisons with peers may be a protective factor for younger children, this may become more problematic for the self-concept of older children (Glenn and Cunningham, 2001).

In addition to comparing themselves with peers, the self-concept of children with intellectual disabilities may be negatively impacted by experiences of stigma or discrimination, which they are more likely to experience than nondisabled peers (Cooney et al., 2006). Belonging to a stigmatised group may result in social exclusion or marginalisation by peers (Dovidio et al., 2000), and in a recent report by the disability charity Enable, 29% of secondary students said they find it difficult to make friends with peers at their school who have intellectual disabilities (Enable, 2017). Disability charities have highlighted the need for schools anti-bullying policies to include preventative strategies such as

introducing understanding of prejudice and diversity to the school curriculum (Equality and Human Rights Commission, 2015). However, only 37% of secondary school pupils report being taught about disability prejudice (Enable, 2017). Yet, young people's social experiences extended outside the school gates (Taylor, 2000) and school-aged children have an awareness of society's stigmatised views towards disability which may also contribute to lower scores on measures of self-concept (Dagnan and Sandhu, 1999).

School is an important context for the development of self-concept in children and young people (Verhoeven et al., 2019), and previous literature has suggested there may be differences in the self-concept scores of young people with intellectual disabilities (Glen and Cunningham, 2001; Dagnan and Sandhu, 1999), compared to mainstream peers. Due to the potential negative social and mental health outcomes associated with poor self-concept, it is important to review and examine existing research of self-concept among children with intellectual disabilities who attend mainstream school, as they are increasingly included in these environments. These findings could inform education providers with information on how best to support the developing self-concept of school-aged children. A previous systematic review examining differences in social comparisons between children, young people and adults from these two groups has recently been completed (Mason-Roberts, 2020). The present review builds on its findings by focusing on measures of self-concept within a school-aged population; specifically, examining measures of global, academic and social self-concept, and exploring the factors which may impact self-concept ratings for this population.

2. Methods

2.1 Search Strategy

This review was completed in accordance with the guidance outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA, Moher et al, 2009).

A search of MEDLINE, EMBASE, PSYCHINFO and British Education Index was carried out on 24.05.2021. The subject headings and keywords of the searches were reviewed, and discussed with university librarians. In order to increase the search sensitivity and reduce the specificity of the searches, to ensure relevant studies were not excluded, broad search terminologies were used rather than specific associated factors.

The final search terms are detailed in Table 1. A full description of the search strategy is included in Appendix 1.2.

Table 1: Search terms

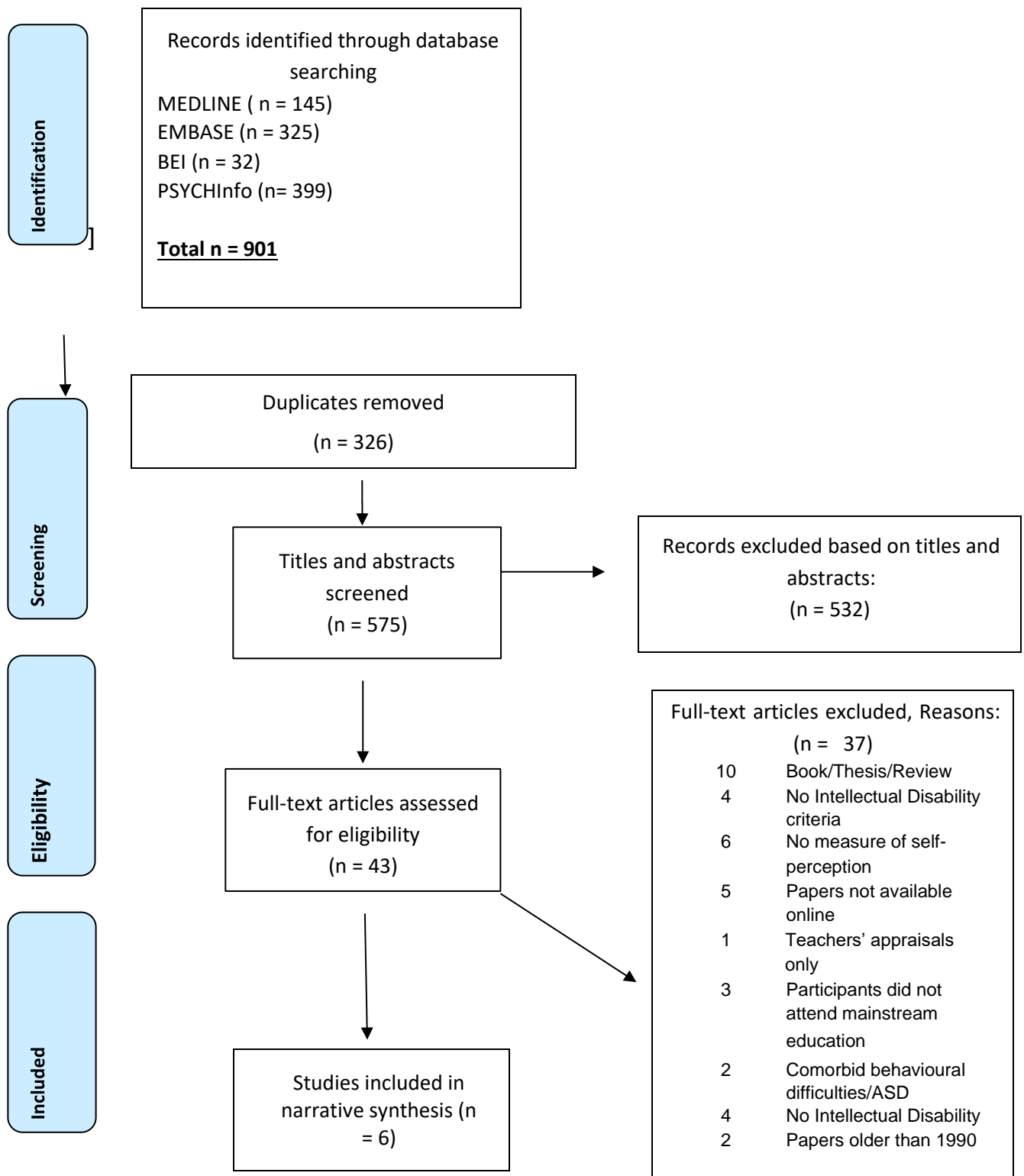
(((mental* or intellectual* or learning) N1 (disab* or disorder* or deficien* or retard*)))
OR
(down* syndrome)
AND
(((school* or education) N2 (mainstream* or special)))
AND
(((social* N1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*)))
AND
(peer#) NOT (“peer review)

2.2 Study Selection

Studies were included in the review if they met the following criteria: i) participants had a diagnosis of intellectual disability; ii) participants attended mainstream school at primary or secondary level (or equivalent for international studies); iii) the study provided a self-reported measure of self-perception (e.g., self-esteem, self-efficacy or perception of learning measures) as part of the design; iv) the study was a full report, published in a peer reviewed journal, v) the study was quantitative or used mixed methods, and vi) was written in English. Studies were excluded if they: i) were discussion papers, literature reviews, case reports, letters, book chapters, dissertations, or if the full text was not available online; ii) they provided no information about how participants' intellectual disability was confirmed or diagnosed, and; iii) the data from participants with intellectual disabilities was combined with the data from other groups (i.e., behaviour or learning difficulties) in the analysis and was not separately listed. There were no restrictions on participants age, setting, or clinical or non-clinical samples.

A total of 901 studies were identified through database searches. Duplicate articles were then removed using Mendeley and manually (N = 326 removed), and the remaining study titles and abstracts were read for relevance and checked against the inclusion criteria (N = 575). The remaining studies were then read in full (N = 43) and the articles which were not relevant were removed (N = 37). A total of six papers were selected for inclusion in the review. This process is outlined in the PRISMA flowchart in Figure 1.1.

Figure 1.1: Flow chart of systematic search process and study selection



Note: ASD = Autism Spectrum Disorder

2.3 Data Analysis

As the studies differed in their methods and reporting of outcomes, it was not possible to conduct a meta-analysis. Instead, a narrative synthesis approach was taken, to examine the quality of the studies and the pattern of findings (Popay et al, 2006).

2.4 Quality Appraisal

The quality rating tool used was the Checklist for Analytical Cross-Sectional Studies (CACSS) (JBI, 2020) (see Appendix 1.3). Johanna Briggs Institute (JBI) checklists have been used in previous systematic reviews concerning intellectual disability populations (Buckley et al, 2020; Portia et al, 2019) and have been recommended for use with reviews involving cross-sectional studies (Ma et al, 2020). The 8-item CACSS covers the following areas: i) appropriate selection of participants, ii) appropriate use of methodology, iii) potential influence of confounders, iv) appropriate use of statistical analysis. In line with the checklist, items were rated as *yes*, *no*, *unclear* or *not applicable*. Each *yes* response was given 1-point, and 0-points were given for *no* or *unclear* responses. This allowed for each study to be given a total rating out of 8, which helped identify overall quality ratings.

In order to establish inter-rater reliability, and to reduce risk of bias, all six of the papers were reviewed by a second rater. There was adequate reliability, indicated by 98% agreement across the checklist items. Any differences of opinion were resolved through discussions.

3. Results

3.1 Quality ratings of studies

There was variability in methodological quality of the included studies. Scores ranged from 2/8 to 7/8 on the JBI CACSS (Table 2). Although there is no specific cut-off score, higher scores indicate greater quality papers. In addition to their score, three items from the JBI CACSS were identified as “key items” used to indicate better quality papers: 1) “Were the study subjects and the setting described in detail?”; 2) “Were the outcome measured in a valid and reliable way?”; and 3) “Was appropriate statistical analysis used?”. These items were chosen to allow for comparisons of relative strengths and limitations to be made across papers, during the narrative synthesis, regarding: number of participants and their characteristics, education setting, measures used, and if appropriate analysis was used, taking into account any potential confounds. The outcomes from the key items and overall score, were then combined to categorise the papers as “relatively strong”, “fair” or “relatively weak” (Table 2). For the synthesis, papers rated as relatively stronger will have greater emphasis placed on their results, than papers who are rated as relatively weak.

Table 2: Quality ratings and assigned category

	<u>Johanna Briggs Institute question numbers</u>									
<u>Paper</u>	1	2	3	4	5	6	7	8	<u>Total</u>	<u>Category</u>
Harter et al (1998)	N	Y	Y	Y	Y	Y	Y	Y	7/8	relatively strong
Coleman and Minnet (1992)	N	N	N	N	N	Y	N	Y	2/8	relatively weak
Huck et al (2010)	N	Y	Y	N	Y	N	N	Y	4/8	fair
Nambiar et al (2020)	Y	Y	Y	Y	Y	N	Y	Y	7/8	relatively strong
Alnahidi et al (2020)	N	N	N	N	Y	Y	N	Y	3/8	relatively weak
Bakker et al (2007)	N	Y	Y	N	Y	Y	N	Y	5/8	relatively strong

Note: Y = met criteria ; N = did not meet criteria

Two papers rated as relatively strong scored 7/8 (Harter et al., 1998; Nambiar et al., 2020). They were found to have considered the risk of bias across the three areas of design, conduct and analysis, and scored a “yes” response on all three of the key items. These papers provided good explanations of how participants were identified and recruited, information regarding how participants diagnosis of intellectual disability was derived, and used validated outcome measures. One paper rated as relatively strong scored 5/8 (Bakker et al., 2010), however they also scored a “yes” response on two of the key items of design and analysis, indicating the authors had undertaken a good consideration of bias. However, their score was lower due to their outcome measures lacking validity; the authors created questionnaires specifically for their study, and only one was validated through factor analysis.

The paper judged as “Fair” (Huck et al., 2010) had a score of 4/8 and scored “yes” on two of the key items. However, there appeared the risk of bias within their paper as the authors did not obtain inter-rater reliability for The Self

Perception Profile for Adolescents outcome measure, and did not take into account potential confounds to the results. However, their participant recruitment, measures used and data analysis were deemed appropriate in addressing their research questions.

The two papers rated as relatively weak had low scores (Coleman and Minnet, 1992 = 2/8 and Alnahidi et al, 2020 = 3/8) and only had positive scores on one key item, indicating their papers were at a higher risk of bias. Information about how the measures were administered were not known for the Alnahidi et al (2020) study, and the authors stated the method used was not appropriate to answer their research question due to confounds (such as cross-cultural differences). However, they did address Type 1 error risks in their analysis and were open about their study's limitations regarding confounds. Coleman and Minnet (1992) conducted appropriate analysis and addressed sociodemographic confounds within their analyses. However, it is unclear how their measures were administered which raises questions about the validity of these results, and there were no inclusion or exclusion criteria stated, making it difficult to assess whether their sample was appropriate to their research question.

3.2 Participant characteristics

Overall, the studies included 2,912 participants; 672 had an intellectual disability (23%), 264 had specific learning difficulties (9%), 279 were low achievers (10%) and 1,697 were described as non-learning disabled (58%). The sample sizes varied greatly, from 17 – 1,295 participants. Four papers

included children aged 9 – 12 years, and one paper recruited adolescents with a mean age of 14 years (Nambiar et al, 2020) (Table 3). All papers included participants with intellectual disabilities, who attend mainstream education. Two papers specified that these students received 1-2 hours of tuition per day, in a resource classroom (Harter et al, 1998; Coleman and Minnet, 1992). Resource classrooms are separate rooms within schools, where children with intellectual disabilities can be taught in smaller groups. Four papers did not specify if students received additional academic support (Alnahidi et al, 2020; Huck et al 2010; Nambiar et al., 2020; and Bakker et al., 2007); and two papers included a control group of students from special schools (Nambier et al., 2020; Bakker et al., 2007).

Table 3: Study design, characteristics, main findings and limitations.

STUDY, LOCATION & QUALITY	DESIGN	AIM/HYPOTHESIS	SAMPLE	ASSESSMENT OF ID	MEASURE OF SELF- CONCEPT	OTHER MEASURES	MAIN FINDINGS	LIMITATIONS
1. Harter et al 1998, USA Quality rating = 7/8 <i>Relatively strong</i>	Cross sectional	1.The intellectual disability group would report more negative self-evaluations for cognitive competence domain than nondisabled peers	-High school students aged 13 – 18 years	- Identified as having Intellectual Disability by school staff according to State of Colorado criteria.	The Self Perception profile for Adolescents (SPPA) (Harter, 1988)	- Importance ratings for each domain on the SPPA, created by the researchers for the purpose of this study.	-Individuals who ranked their self- worth as high, reported much lower importance ratings for domains which they felt they had limitations. No significant difference between groups. -Perceived social appeal was the greatest contributor to participants' sense of worth, irrespective of educational status. -Intellectual Disability group had lower ratings of cognitive competence than control group.	-No measure of IQ -Importance scale was not validated measure
	Between groups	2.There would be no difference between the importance students place on different domains of the Self- Perception Profile, between student groups. 3.Students from both groups who report low self-worth would give higher ratings of importance to domains in which they feel inadequate.	-118 Intellectual Disabilities (males = 72; females = 46) -235 without disabilities (males = 102; females = 133).					
2. Colman and Minnett 1992, USA	Cross- sectional Between- groups	Explored the difference in perceived social competencies between children with intellectual disabilities and children	-School students aged 8 – 12 years	- Identified by Texas school district as having intellectual disability	Harter Perceived Competence Scale for	Peer Relations and Parent Relations factors of the Self- Description	-There were no significant differences between the social competency scores of children with Intellectual Disability and LA children.	No IQ measures No comparison to social competencies of non-ID peers.

**Quality rating =
2/8**

Relatively weak

with low academic
achievement

- 85 ID (male =
54; female = 31)

85 Low
Achieving (LA)
peers (male =
54; female = 31)
matched on
grade, age, sex
and academic
achievement
scores.

Children
(HPCSC)
(Harter, 1982).

Questionnaire
(SDQ) (Marsh
and Parker,
1984).

Children with Intellectual Disability
considered themselves comparable
to other LA children in terms of
social self-concept.

Social rating scale
used has no
measure of validity
or reliability.

Loneliness
Questionnaire
(Asher et al,
1984)

The Intellectual Disability group
reported themselves to be far less
lonely than their peers. This
difference was found to be
significant.

Demographics of
sample not
comparable to
suburban, rural or
small-rural
environments.

Social Rating – 5
Point scale
developed for this
study by the
researchers.

Children with Intellectual Disabilities
were viewed by peers as being
better liked than the LA children.
This difference was found to be
significant.

No significant
values reported for
Self-Concept.

Teacher ratings –
scales developed
for this study by
researchers

3. Huck et al 2010, Australia Quality rating = 4/8 Fair	Cross-sectional	To measure the perceived competence and acceptance of younger children with intellectual disability	17 children with intellectual disability (males = 11; females = 6; mean age = 9 years)	assessed by psychologist in preschool year as having a mild to moderate intellectual disability (majority moderate intellectual disability)	pictorial scale of perceived competence and social acceptance for young children (Harter and Pike, 1983)	academic performance calculated by calibrating a sample standard of work (numeracy and literacy) produced by the children with intellectual disability against a sample standard work produced by peers. Marked by trained teachers.	16/17 participants with intellectual disability rated their competence and acceptance as positive.	pspcs measure designed for children aged 4 – 7 years.
	Between groups	To compare these scores with measures of academic performance and social status, as perceived by teachers and peers.	all participants included in a larger study.			Social status-involved rating by class peers of the degree to which they liked the child with a disability in their class.	participants rated their self-concept as high, and these scores were higher than typically developing peers' scores.	no interrater reliability data on scoring of pspcsa. small sample size
4. Nambiar et al 2020, India	Cross sectional	Explored children's experiences of peer victimisation, and correlated these with	Recruited from the outpatient and inpatient services of a Child and	Participants' IQ scores ranged between 50	Rosenberg Self-Esteem Scale (RSES,	The Multi-Dimensional Peer Victimization	<u>Self-Esteem</u> - 47.5% reported a self-esteem score of <15, indicating problematic low self-esteem.	Sample not representative due to logistic constraints.

<p>Quality rating = 7/8</p> <p>Relatively strong</p>		measures of self-esteem.	Adolescent Psychiatry Department and Special Schools	85 (Verified by Consultant Clinical Psychologist at the Psychiatry Department)	Rosenberg, 1965).	Scale (MPVS, Mynard and Joseph, 2000)	Significantly greater self-esteem reported among participants from special schools.	Measures are not validated in Indian context.
			40 children (Male = 25; Female = 15; Mean age = 14.6 years; Mild Intellectual Disability = 25; Borderline Intellectual Disability = 15; Regular school = 23; Special school = 17).					No control group used.
<p>5. Alnahidi et al 2020, Saudi Arabia/ Germany</p> <p>Quality rating = 3/8</p> <p>Relatively weak</p>	<p>Cross sectional</p> <p>Between groups</p>	To compare students' perceptions of inclusion between Saudi and German students	<p>-Saudi students = 888 (Males = 33%; Females = 67%; 70 = SEN; ages = 8 – 12 years)</p> <p>- German students = 699 (Males = 53%; Females = 47%; 54 = SEN; Ages 11 – 15 years).</p>	Identified by school as having Intellectual Disability	Perception of Inclusion Questionnaire (PIQ, Venetz et al, 2015)	None	<p><i>Academic self-concept:</i> Saudi students with Intellectual Disability reported lower scores than Saudi students without Intellectual Disability</p> <p>Saudi students generally reported higher levels of Social Inclusion, School Well-Being and Academic Self-Concept, than German students.</p> <p>German students with Intellectual Disability reported significantly lower scores on measures of academic self-concept, than other students.</p>	<p>Risk of type 1 error from running multiple t-tests</p> <p>Data excluded from analysis in order to have comparable groups.</p> <p>Only analysed at item-level, not domain-level response tendency to</p>

Likert scales may differ across culturally distinct countries may result in ineffective way of analysing data.

Doesn't examine confounds such as age, gender etc.

6. Bakker et al 2007, Netherlands Quality rating = 5/8 <i>Relatively stronger</i>	Cross-sectional	To explore the sociometric status and self-image of children with Intellectual Disability in general and special education, in the Netherlands.	- 1,295 participants recruited	- Teachers identified students with	Questionnaire measuring self-image (developed by researchers)	Sociometric Status assessed using a method developed from Cole et al (1982).	<u>General Education</u> <i>Sociometric status</i> - Children with General Intellectual Disability are more likely to be judged by peers as socially "rejected" than those with SLD or LA	Self-image questionnaire had poor validity
	Between subjects		General school = 861; Male = 49.5%; Female = 50.5%; Age range = 9 – 12 years; General Intellectual Disability N = 74; Specific learning difficulties N = 99; Special school = 439; Male = 65.1%; Female = 34.9%; Age range = 9 – 12 years;	General ID (IQ's <85) and Specific LD's (IQ's >85) from their classes.		Questionnaire measuring performance level of students with Intellectual Disability (developed by researchers)	<i>Self-Image</i> - Students with General Intellectual Disability demonstrated lower mean self-image scores concerning relationship with classmates, than other groups. These scores varied by student age. <u>Special Education</u> <i>Sociometric status</i> - Children with General Intellectual Disability are likely to be judged	Teacher measure of performance was subjectively based - used report cards, not standardised test scores. No measure of validity or reliability for sociometric status questionnaire.

General
Intellectual
Disability = 213; Specific
learning difficulties = 165;
Low Achieving =
58

Questionnaire
measuring nature
of students
Intellectual
Disability
(developed by
researchers)

as “average” by peers, which is the
same as those with SLD and LA.

Children with General
Intellectual Disability were judged to
be more popular (11%) than the LA
group (9%) but less popular than the
SLD group (16%).

Self-image – self-image scores were
not related to diagnostic label or
performance, however girls with
General Intellectual Disability
demonstrated lower feelings of self-
worth and competence than boys.

3.3 Study characteristics

Although all studies included a measure of global self-concept, the outcome measure used varied across studies. Other outcomes which explored specific areas of self-concept were also used, including: importance ratings participants gave to each domain on the self-concept measure (Harter et al, 1998); perceived peer and social relationships (Coleman and Minnet, 1992; Huck et al, 2010; Nambiar et al, 2020; Alnahidi et al, 2020; Bakker et al, 2007); and perceived academic status (Huck et al, 2010, Alnahidi et al, 2020; Bakker et al, 2007) (Table 3). For this reason, this review will consider the evidence for global self-concept, academic self-concept, social self-concept and importance ratings.

3.4 Results

The results below outline the findings of the self-concept scores of children and adolescents in mainstream education settings. The measures used vary between global and specific measures of self-concept. As such, the results will outline the findings from these difference measures in turn, exploring the findings from global measurements of self-concept, as well as the impact of social and academic domains on global self-concept within this population.

3.4.1 Global Self-concept

Across all six studies, four included multi-factor measures of self-concept. There were mixed findings from the different studies (Table 3).

Harter et al (2012) adopted the view that self-perceptions are constructed by multiple domains, which change across age and context. Their study (Harter et al, 1998) measured self-concept across eight different domains: general cognitive competence, athletic competence, job competence, peer likeability, close friendship, romantic appeal, physical appearance, behavioural conduct and compared these to a domain of global self-worth. Within their sample, they found that indices related to peer social appeal (such as physical appearance, romantic appeal and peer likeability) were highly correlated to scores of global self-concept. This indicates that perceived acceptance from others is an important factor in the self-concept of adolescents with intellectual disabilities. Furthermore, they found that students with intellectual disabilities made fewer positive self-evaluations ($M = 2.75$) than students without intellectual disabilities ($M = 3.06$, $p < 0.001$), on the measure of global self-concept. Nambier et al (2020) reported similar results in their study, where 47.5% of participants with intellectual disabilities reported problematic levels of poor self-esteem ($M = 14.95$, $SD = 5.43$). Furthermore, these scores were lower among students with intellectual disabilities who attended mainstream schools (Median = 20) than special schools (Median = 12), $U = 77.5$, $p < 0.001$. However, these results may have been impacted by cultural factors regarding stigma towards individuals with intellectual disabilities in some regions of India. Furthermore, it was suggested that the lack of resource rooms to provide additional support resulted in poorer academic outcomes for students with intellectual disabilities, which may have impacted on their self-esteem (Cornelius and Balakrishnan, 2012; Karande et al., 2008). This could

account for the lower ratings for children attending mainstream school, compared to those attending special schools.

Bakker et al (2007) examined feelings of self-worth among children with intellectual disabilities across mainstream and special education settings.

Contrary to the results reported above, they did not find significant differences between the self-worth scores of children with intellectual disabilities in mainstream classrooms ($M = 2.33$, $SD = 0.57$) and those of average achieving students ($M = 2.33$, $SD = 0.56$). There was also no relationship found between feelings of self-worth and diagnostic label, across mainstream ($M = 2.14$, $SD = 0.45$) and special ($M = 2.22$, $SD = 0.45$) education settings.

Additionally, Huck et al (2010) showed that students with intellectual disabilities attending mainstream schools rated their self-concept scores within the “very high” range ($M = 3.54$, $SD = 0.57$) on the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children scale. Furthermore, Coleman and Minnet’s (1992) study compared the social self-concept scores of children with intellectual disabilities across school settings. Multivariate analysis demonstrated no significant difference between the scores of those who attended mainstream schools and those who attended special schools. Overall, these studies highlight the complexities involved in measurements of global self-concept and the wide number of variables which can impact on ratings (Table 3).

3.4.2 Academic/Cognitive Self-Concept

Three studies specifically examined students’ perceptions related to their academic or cognitive self-concept (Table 3). They all found that students with

intellectual disabilities attending mainstream schools scored lower on measures of cognitive or academic self-concept, than their peers without intellectual disabilities. Harter et al (1998) found that participants with intellectual disabilities rated their cognitive competence as lower ($M = 2.41$) than their peers ($M = 3.02$, $p < 0.001$).

Alnahidi et al (2020) compared the academic self-concept scores of students with intellectual disabilities and no-disability, across mainstream schools in Saudi Arabia and Germany. They found that students with intellectual disabilities from both countries were significantly more likely to report lower scores than their peers without intellectual disabilities on measures such as: "I'm able to solve very difficult exercises" ($M = 2.63$; $M = 3.16$, $p < 0.004$, $d = 0.52$, respectively), and "I'm a fast learner" ($M = 2.7$; $M = 3.36$, $p < 0.004$, $d = 0.44$, respectively). Although their results showed Saudi students rated their self-concept higher than German students, the authors thought this could be explained by cross-cultural reporting bias on likert scales which is a limitation of this study; as the Saudi students tended to assign higher ratings to items, whereas German students' scores tended to be more central (Walker, 2007). They concluded that for cross-cultural comparisons, comparing mean scores on likert scales is not an appropriate methodology.

Finally, Bakker et al (2007) from the USA found a significant effect of diagnostic label on competence ratings ($f(4, 846) = 11.81$, $p = 0.001$) and on perception of school tasks ($t(846) = -4.67$, $p < 0.001$, $d = -0.58$), in mainstream school. Overall, these findings suggest that students with intellectual disabilities are

likely to report lower scores on measures of academic or cognitive self-concept, than students without disabilities (Table 3).

3.4.3 Social Perceptions

Five papers examined participants' social self-perceptions. Once again, mixed results were reported (Table 3). Three studies report no difference in the social self-perception scores of students with intellectual disabilities compared to typically developing peers, in mainstream schools. One paper (Coleman and Minnet, 1992) reported higher social self-perception scores amongst students with intellectual disabilities, and the remaining papers (Table 3) reported the opposite.

Harter et al's (1998) study found that students with intellectual disabilities reported more negative perceptions of their likeability by peers ($M = 2.99$), than typically developing peers ($M = 3.21$, $p < 0.01$). The authors hypothesised that, as the students with intellectual disabilities spend part of their school day in a resource classroom, this may contribute to feelings of isolation from mainstream class peers. However, they found no significant differences between students' perceptions of friendships (intellectual disability $M = 3.33$; typically developing $M = 3.46$); or on ratings of physical appearance (intellectual disability $M = 2.48$; typically developing $M = 2.67$).

Alnahidi et al's (2020) study also explored social ratings among participants, and found no significant differences of social ratings between groups, or across cultures. There was no significant difference between Saudi students with

intellectual disabilities ($M = 3.34$) and typically developing peers ($M = 3.52$) on the question “I have lots of friends in class”, nor with the German sample (intellectual disabilities $M = 3.34$; typically developing $M = 3.52$). German students with intellectual disabilities also reported no difference on measures of social inclusion compared to students without disabilities: “I have a lot of friends in my class” (intellectual disability $M = 3.09$; typically developing $M = 3.23$, $p = 0.280$); “I get along very well with my classmates (intellectual disability $M = 3.22$; typically developing $M = 3.36$, $P = 0.16$); “I have very good relationships with my classmates” (intellectual disability $M = 3.35$; typically developing $M = 3.32$, $P = 0.754$).

However, due to a number of limitations, this study was rated as poor quality and high risk of bias using the Johanna Briggs Institute. Firstly, the authors only examined their data at the item level, therefore, it is difficult to make more broader generalisations about how these findings relate to overall domains of social perceptions and cognitive perceptions, as no information from factor analysis is known about how these items load or relate to each other. There are also cross-cultural differences with using Likert scales as a measure, which makes it difficult to draw comparisons across countries. Finally, the authors only employed one method of collecting data, and did not combine these with teacher or parent ratings, for example.

Similarly, Huck et al's (2010) study saw a small negative correlation between measures of peer acceptance, and measures of peer ratings of social status, for students with intellectual disabilities in mainstream schools. However, this difference was found to be non-significant ($r = -2.57$, $p = 0.446$). Students with

intellectual disabilities rated their perception of peer acceptance as positive, and all children were given a rating of at least “okay” by their peers, indicating acceptance. The small sample size is a limitation of this study (Table 3); the researchers only recruited participants who were already taking part in a larger study, and the results may be impacted by selection bias.

Bakker et al (2007) found there was a significant relationship between diagnostic label and mean scores, on perceived relationships with classmates in mainstream settings ($t(846) = -2.12$, $p = 0.3$, $d = -0.20$). Students with intellectual disabilities reported poorer peer relationships ($M = 2.14$) than the other groups (Learning Difficulties $M = 2.26$; Low Achieving $M = 2.18$; and Average Achieving $M = 2.24$). Interestingly, there was no significant interaction found for diagnostic label and mean scores for relationships with classmates within special education setting. The authors also found a relationship between academic achievements and relationships with peers; notably that the highest achievers reported the best relationships with peers (Table 3).

Conversely, Coleman and Minnet’s (1992) study found that students with intellectual disabilities reported higher scores on perceived social factors than students without disabilities. They found a significant multi-variate main effect for disability status and scores on perceived social network with peers in their mainstream class, $f(6, 153) = 5.98$, $p < 0.001$, meaning that students with intellectual disabilities perceived themselves to have better social networks, than peers without disabilities (Table 3). Further analysis showed children with intellectual disabilities scored significantly better on the loneliness questionnaire ($M = 40.46$) than those without disabilities ($M = 50.54$) (where lower score indicates feeling less lonely). This suggests students with intellectual disabilities

felt more included by peers, than those without disabilities. However, a limitation of this study is the researchers did not use a measure of social competencies, meaning it was not possible to compare the social skills between groups. Another limitation of this finding is the social rating scale used for this study, which was developed by the researchers, lacks evidence of validity. This means the results may not be a reliable measure of student's social ratings and the results may not generalise.

3.4.4 Self-concept and Importance Ratings

Harter et al's (1998) paper, examined the importance participants placed on the eight different items which make up the Harter Self Perception Profile for Adolescents (Table 3). Across the two groups, the domains rated as most important were: Close Friendships ($M = 3.17$); Job Competence ($M = 3.19$) and Physical Appearance ($M = 3.17$). A MANOVA analysis revealed no significant difference in importance of these domains between groups. However, MANOVA analysis suggests that the intellectual disability group rated the domain of Cognitive Competence ($M = 2.84$) as significantly more important than the typically developing group ($M = 2.45$). Furthermore, the authors reported a correlation between perceived competency in important domains, and self-worth scores across both groups. The authors highlighted that dimensions of perceived social appeal were also important contributing factors to participants sense of self-worth as a person, irrespective of educational status. However, a limitation of these findings is the importance questionnaire was developed by the researchers for this study, and lacks validity and

reliability.

4. Discussion

Due to the small number of studies included in this review, it is difficult to generalise from the findings, regarding self-concept among children and adolescents with intellectual disabilities who attend mainstream schools. Overall, on measures of global self-worth, mixed findings were reported. Two studies reported students with intellectual disabilities to have more problematic levels of self-esteem, and make significantly fewer positive self-evaluations, when compared to non-disabled peers (Harter et al., 1998; Nambiar et al., 2020) (Table 3). Both of these papers were given relatively strong quality ratings, and both utilised validated measures for data collection, therefore these findings need to be taken seriously. However, the results from the remaining studies suggest either no differences (Bakker et al., 2007; Coleman and Minnet, 1992) between self-concept scores across groups, or that students with intellectual disabilities rated themselves higher than typically developing peers on measures of self-concept (Huck et al., 2010). These were poorer quality studies and their findings should be interpreted with caution. Furthermore, there are differences in the ages of the participants included in these studies; Bakker et al. (2007), Coleman and Minnet (1992), and Huck et al. (2010) recruited younger participants (age range: 8 – 12 years) than Harter et al (1998) and Nambiar et al (2020), who recruited adolescent participants (age range: 13 – 18 years). Cunningham and Glenn, (2004) suggested that younger children with intellectual disabilities may not have developed the ability to make social comparisons with their typically developing peers, and that this might help them to maintain a positive sense of self in line with their non-disabled peers.

The findings of this review also suggest that students with intellectual disabilities, who attend mainstream schools, scored lower on specific measures of cognitive and academic self-concept, compared to class peers without disabilities (Harter et al., 1998; Alnahidi et al., 2020; Bakker et al., 2007). These findings were consistent across all studies and are in line with previous research, which suggest that students with intellectual disabilities in mainstream schools are aware of their academic limitations and make negative comparisons between their academic performance and those of other students without disabilities (Coleman, 1985; Renick and Harter, 1989; Kelly and Norwich, 2003). Interestingly, these findings spanned across different participant age ranges, which suggest younger children are able to make social comparisons regarding academic abilities. This appears to contradict the theories of Cunningham and Glenn (2004) and warrant further investigation with future research. These studies also span different countries and cultures, suggesting that lower cognitive self-concept scores may be a shared characteristic among students with intellectual disabilities, who attend mainstream schools. These findings are robust, and perhaps it is not surprising that students with intellectual disabilities report lower academic confidence, given the academic focus which occurs in mainstream school settings.

Mixed results were reported for measures of social self-concept. Whilst most of the studies reported no difference in the social self-perception scores of students with intellectual disabilities (Harter et al., 1998; Alnahidi et al., 2020; Huck et al., 2007), one study reported students with intellectual disabilities reported a poorer perception of their relationships with peers, than typically developing classmates (Bakker et al., 2007). This is in line with previous

research which suggests students with disabilities have lower perceived peer acceptance than non-disabled peers (Taylor et al., 1987). It may be that students with disabilities are aware of stigmatising attitudes and feel a sense of difference from peers (Jenkins and Heinen, 1989), which may impact on their perceived relationships with other students. These findings appear to be in keeping with real world reports from adolescents and adults with intellectual disabilities, who report feelings of loneliness and social isolation (Merrells et al., 2019; Enable, 2017), and align with the results from Bakker et al (2007), Harter et al (1998) and Alnahidi et al (2020). The remaining study found that students with intellectual disabilities reported greater perceived social networks and less loneliness, than non-disabled peers (Huck et al., 2010). Although these findings are mixed, the results suggest that there may be some factors which impact on perceived relationships with peers. It is noted that these findings span different age ranges, and it would be interesting for future research to explore if there are some factors which act as a “buffer” to maintain or increase social relationships with peers; particularly those of older children, as research suggests feelings of isolation continue into adulthood (Merrells et al., 2019).

Finally, Harter et al (1998) examined which factors, related to self-concept, students with intellectual disabilities rated as most important to them. The findings from their study suggest that domains regarding perceived peer and social acceptance were rated as most important, and had a greater influence on their global self-concept ratings, when compared to domains such as cognitive or athletic competence. These results support the view that perception of self-worth is not necessarily affected by school performance. Instead, students with intellectual disabilities use other life domains to judge

their feelings of self-worth, such as relationships with parents, siblings and peers (Gans et al., 2003; Grolnick and Ryan, 1990).

4.1 Methodological limitations and future research

A limitation of this review is the small number of papers included, with mixed quality ratings. The mixture of quality ratings is mainly a result of the cross-sectional designs which meant that few confounding variables were controlled, such as: age, gender, time spent in mainstream education, and number of positive relationships with influential adults (Harter, 1999). Due to this, care should be taken when interpreting the findings. The quality ratings of future studies could be improved through measures which control for these variables, such as use of additional outcome measures utilising reports from teachers or parents, or using analysis of variance to explore the impact of factors such as age, gender, socio-economic background.

Furthermore, a limitation of this review is that it only focused on the perceived self-concept of a school-aged population. The literature on social comparison theories suggest self-concept is dynamic, and changes over the lifespan (Cunningham and Glenn, 2004). Future research could aim to explore the perceived self-concept of individuals with intellectual disabilities who have left school. It would be important to understand if and how young people's self-concepts change across key life transitions. Research suggests a continued lack of opportunities for young people with intellectual disabilities once they have left school, in terms of attending further education, training and entering employment, compared to non-disabled peers (Banks et al., 2007; McConkey

et al., 2017). It would be important to build on the findings of this review by exploring the self-concept of young people as they transition into further education colleges, the workplace, or more independent living settings.

There were a lack of psychometrically validated measures used in the studies included in this review. Harter's Self-Perception Profile for Children, for example, is validated in normative populations and does not necessarily take into account the life experiences of individuals with disabilities (Llewellyn and Chung, 1997; Woodgate et al., 2020). For example, children and young people with intellectual disabilities may receive more or exaggerated praise for small achievements, than their non-disabled peers (Huck et al., 2010), which could explain higher self-concept scores for younger children. The lack of opportunities to develop these skills, could impact their responses on self-concept measures. Only one study (Harter et al., 1998) performed a factor analysis to determine if the measure was suitable for use with their intellectual disability group. Furthermore, four studies included measures designed by their researchers, but failed to examine the test-retest reliability, internal consistency, or content validity for their populations. If future studies include novel measures, it would be important to first validate these for use in their target population through pilot studies.

Additionally, the studies included in this study were carried out in a range of different countries, which makes direct comparison of results difficult. In particular, the definition of Intellectual Disability may have differed between different countries. This may have resulted in differences in the nature of participants who took part in the different studies. Moreover, the educational

systems and schooling of children with intellectual disabilities are also likely to differ across countries, with potentially different impacts on the children's self-concepts. These range of factors may limit the conclusions which can be drawn from across the studies and applied to young people with Intellectual Disabilities within the United Kingdom.

Finally, this review only included quantitative studies from a school-age population. More recent work in the area of intellectual disabilities has employed qualitative methods to gain insight into participants views, in the context of their lives (Rushbrook et al., 2014; Monteleone and Forrester-Jones, 2016; Banks et al., 2009; Jahoda et al., 2010). Future research could aim to review the qualitative literature regarding self-concept in this population, to highlight recurring themes.

4.2 Implications

The findings from this review suggest that students with intellectual disabilities may have lower levels of self-esteem and may report less positive global and cognitive self-concept scores than non-disabled peers, in a mainstream education setting. These findings could have important implications for mainstream schools, where children should be encouraged to achieve their best, academically; however, importance could also be placed on other aspects of school life such as participating in sports, charity work, group activities, and these may promote greater inclusion within the school context. This may be reflected in school's ethos, whereby encouraging students to develop their own unique talents may hold equal importance to academic outcomes.

4.3 Conclusions

This review has highlighted the relationships between measures of global, social and academic self-concepts in students with intellectual disabilities who attend mainstream school. In particular, the findings suggest that students appear to maintain a robust sense of self, despite recognising their academic weakness in mainstream settings. These findings could be used to inform educational practices, whereby schools recognise and promote the individual talents of students, as well as academic achievements, to promote the development of positive self-concept. Additionally, greater efforts could be made to promote social relationships between students, and reduce stigma, particularly among older school students.

References

- Alnahdi, G. H., & Schwab, S. (2020). Inclusive education in Saudi Arabia and Germany: students' perception of school well-being, social inclusion, and academic self-concept. *European Journal of Special Needs Education*, 1-14.
- Bakker, J. T., Denessen, E., Bosman, A. M., Krijger, E. M., & Bouts, L. (2007). Sociometric status and self-image of children with specific and general learning disabilities in Dutch general and special education classes. *Learning Disability Quarterly*, 30(1), 47-62.
- Banks, P., Jahoda, A., Dagnan, D., Kemp, J., & Williams, V. (2010). Supported employment for people with intellectual disability: The effects of job breakdown on psychological well-being. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 344-354.
- Bong, M., & Skaalvik, E. M. (2003). Academic self-concept and self-efficacy: How different are they really?. *Educational psychology review*, 15(1), 1-40.
- British Psychological Society (2015) *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. BPS Publication. Online <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Guidance%20on%20the%20Assessment%20and%20Diagnosis%20of%20Intellectual%20Disabilities%20in%20Adulthood.pdf> [last accessed 23.09.2021].

Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., ... & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and metaanalysis. *Australian & New Zealand Journal of Psychiatry*, 54(10), 970-984.

Coleman, J. M. (1985). Achievement level, social class, and the self-concepts of mildly handicapped children. *Journal of Learning Disabilities*, 18, 26-30.

Coleman, J. M., McHam, L. A., & Minnett, A. M. (1992). Similarities in the social competencies of learning disabled and low achieving elementary school children. *Journal of Learning Disabilities*, 25(10), 671-677.

Cooley, E. J., & Ayres, R. R. (1988). Self-concept and success-failure attributions of nonhandicapped students and students with learning disabilities. *Journal of learning disabilities*, 21(3), 174-178.

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, 50(6), 432-444.

Crabtree, J., & Rutland, A. (2001). Self-evaluation and social comparison amongst adolescents with learning difficulties. *Journal of Community & Applied Social Psychology*, 11(5), 347-359.

Connolly, J. (1989). Social self-efficacy in adolescence: relations with selfconcept, social adjustment, and mental health. *Canadian Journal of*

Behavioural Science/Revue canadienne des sciences du comportement, 21(3), 258.

Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, 43(5), 372-379.

Davies, C., & Jenkins, R. (1997). 'She has different fits to me': how people with learning difficulties see themselves. *Disability & Society*, 12(1), 95-110.

Dovidio, J. F., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1–28). Guilford Press.

Enable (2017) #IncludED in the Main?! 22 Steps on the journey to inclusion for every pupil who has a learning disability.

<https://www.enable.org.uk/wpcontent/uploads/2017/08/IncludED-in-the-Main-22-Steps-on-the-Journey-to-Inclusion.pdf> [last accessed 23.07.2021]

Equality and Human Rights Commission (2015) Prejudice-based bullying in Scottish schools: A research report

https://www.equalityhumanrights.com/sites/default/files/prejudicebased_bullying_in_scottish_schools_research_report_0.pdf [last accessed 13.07.2021]

Festinger, L. (1954) A theory of social comparison processes. *Human Relations*, 7, 117-140

Fields, D., & Enyedy, N. (2013). Picking up the mantle of “expert”: assigned roles, assertion of identity, and peer recognition within a programming class. *Mind, Culture, and Activity*, 20(2), 113–131.

Finlay W. M. L. & Lyons E. (2000) Social categorisations, social comparisons and stigma: presentations of self in people with learning difficulties. *The British Journal of Social Psychology* 39, 129–146.

Gans, A. M., Kenny, M. C., & Ghany, D. L. (2003). Comparing the self-concept of students with and without LD. *Journal of Learning Disabilities*, 36, 287-295.

Glenn, S., & Cunningham, C. (2001). Evaluation of self by young people with Down syndrome. *International Journal of Disability, Development and Education*, 48(2), 163-177.

Griffiths, A. W. (1970). Self-concept in remedial work with dyslexic children. *Academic Therapy*, 6, 125-133.

Grolnick, W. S., & Ryan, R. M. (1990). Self-perceptions, motivation, and adjustment in children with LD: A multiple-group comparison study. *Journal of Learning Disabilities*, 23, 177-184

Harter, S., & Pike, R. (1984). The pictorial scale of perceived competence and social acceptance for young children. *Child development*, 1969-1982.

Harter, S., Whitesell, N. R., & Junkin, L. J. (1998). Similarities and differences in domain-specific and global self-evaluations of learning-disabled, behaviorally disordered, and normally achieving adolescents. *American Educational Research Journal*, 35(4), 653-680.

- Ho, P., Bulsara, M., Downs, J., Patman, S., Bulsara, C., & Hill, A. M. (2019). Incidence and prevalence of falls in adults with intellectual disability living in the community: a systematic review. *JBIC Evidence Synthesis*, 17(3), 390-413.
- Huck, S., Kemp, C., & Carter, M. (2010). Self-concept of children with intellectual disability in mainstream settings. *Journal of Intellectual and Developmental Disability*, 35(3), 141-154.
- Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, 66(3), 521-534.
- Jenkins, J. R., & Heinen, A. (1989). Students' preferences for service delivery: Pull-out, in-class, or integrated models. *Exceptional Children*, 55(6), 516-523.
- Kelly, N., & Norwich, B. (2004). Pupils' perceptions of self and of labels: Moderate learning difficulties in mainstream and special schools. *British Journal of Educational Psychology*, 74(3), 411-435.
- Llewellyn, A., & Chung, M. C. (1997). The self-esteem of children with physical disabilities—problems and dilemmas of research. *Journal of Developmental and Physical Disabilities*, 9(3), 265-275.
- Ma, L. L., Wang, Y. Y., Yang, Z. H., Huang, D., Weng, H., & Zeng, X. T. (2020). Methodological quality (risk of bias) assessment tools for primary and secondary medical studies: what are they and which is better?. *Military Medical Research*, 7(1), 1-11.

Mason-Roberts, S. K. (2020). *Relating to others: the role of social stressors and social comparisons for individuals with intellectual disabilities* (Doctoral dissertation, University of Glasgow).

McConkey, R., Kelly, F., Craig, S., & Keogh, F. (2017). A longitudinal study of post-school provision for Irish school-leavers with intellectual disability. *British Journal of Learning Disabilities*, 45(3), 166-171.

Merrells, J., Buchanan, A., & Waters, R. (2019). "We feel left out": Experiences of social inclusion from the perspective of young adults with intellectual disability. *Journal of Intellectual & Developmental Disability*, 44(1), 13-22.

Monteleone, R., & Forrester-Jones, R. (2017). 'Disability means, um, dysfunctioning people': a qualitative analysis of the meaning and experience of disability among adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 301-315.

Nambiar, P., Jangam, K., Roopesh, B. N., & Bhaskar, A. (2020). Peer victimization and its relationship to self-esteem in children with mild intellectual disability and borderline intellectual functioning in regular and special schools: An exploratory study in urban Bengaluru. *Journal of Intellectual Disabilities*, 24(4), 474-488.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., et al. (2006) *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews* (pp. 1–92) Lancaster: University of Lancaster

Renick, M. J., & Harter, S. (1989). Impact of social comparisons on the developing self-perceptions of learning-disabled students. *Journal of*

Educational Psychology, 81, 631-638.

Rushbrooke, E., Murray, C., & Townsend, S. (2014). The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 27(6), 531-541.

Scottish Executive (2000) *The Same as You? A Review of Services for People with Learning Disabilities*. Scottish Executive, Edinburgh.

Scottish Government (2000) *The Standards in Scotland's Schools etc. Act*.

Scottish Government Department of Education

<https://www.legislation.gov.uk/asp/2000/6/contents> [last accessed 23.07.2021]

Spilt, J. L., Van Lier, P. A., Leflot, G., Onghena, P., & Colpin, H. (2014).

Children's social self-concept and internalizing problems: The influence of peers and teachers. *Child development*, 85(3), 1248-1256.

Taylor, A. R., Asher, S. R., & Williams, G. A. (1987). The social adaptation of mainstreamed mildly retarded children. *Child Development*, 58, 1321–1334.

Taylor S. J. (2000) 'You're not a retard, you're just wise.' *Journal of Contemporary Ethnography* 29, 58 – 92

Todd S. (2000) Working in the public and private domains: staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research* 44, 600-20

United Nations Convention on the Rights of the Child, November 1989, URL:
 extension://pjmlamaindkoemaaofddboidllnogmhe/https://downloads.unicef.org.uk/wpcontent/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_adal_sd=www.unicef.org.uk.1626686969983&_adal_ca=so%3Ddirect%26me%3Dnone%26ca%3Ddirect%26co%3D(not%2520set)%26ke%3D(not%2520set).1626686969983&_adal_cw=1626686966352.1626686969983&_adal_id=950c971c-0d04-41db-865fdb158119c21b.1626686966.1.1626686966.1626686966.dd594aa8-ec31-48a4-9958a51feeb8cdb1.1626686969983&_ga=2.267312269.2054258647.1626686964-1158301058.1626686964 (Last accessed: 19.07.2021).

Verhoeven, M., Poorthuis, A.M.G. & Volman, M. The Role of School in Adolescents' Identity Development. A Literature Review. *Educational Psychology Review* **31**, 35–63 (2019)

Woodgate, R. L., Gonzalez, M., Demczuk, L., Snow, W. M., Barriage, S., & Kirk, S. (2020). How do peers promote social inclusion of children with disabilities? A mixed-methods systematic review. *Disability and Rehabilitation*, **42**(18), 2553-2579.

Chapter Two: Major Research Project

Moving to further education college: the changing self-perceptions and sense of belonging of young people with intellectual disabilities

Prepared in accordance with the author requirements for the Journal of Applied Research in Intellectual Disabilities (JARID); Appendix 1.1

Plain English Summary

Background: Research suggests that how young people with intellectual disabilities view themselves can be influenced by different life experiences. Unfortunately, for people with intellectual disabilities this can include being bullied or being discriminated against because of their disability. However, people's views can change as they grow older and have more control of their lives. There has been little research about how young people with intellectual disabilities' views about themselves change when they leave school and move to further education college.

Aims: This study aimed to ask young people with intellectual disabilities, who attend college in the West of Scotland, how they experienced moving from school to college. We also wanted to look at how this changed the young people's views of themselves. We also asked about their experiences of stigma.

Methods: Four young people with intellectual disabilities (aged 18 – 21), who were attending further education college, took part in this study. Each person was interviewed by the researcher over MS Teams. They were asked about their move to college and their experience of stigma. The interviews were recorded and analysed using a method called Interpretative Phenomenological Analysis. This approach involves looking very closely at what people say, to try to understand what their experiences mean to them.

Results: There were five main areas that people talked about. 1) A sense of difference; 2) Being part of it; 3) A changing sense of self; 4) College and new opportunities; 5) I can do it. The transition to college was found to be a positive experience for all participants.

Conclusion: On the whole, it seemed that moving to college had helped the young people to feel more grown up and accepted for who they are. It is hoped this information will help people look into the options that are available to young people with intellectual disability, when they leave school. This is important because it might help people with intellectual disabilities keep developing their view of themselves as they move into adulthood.

References:

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, 50(6), 432-444.

Cunningham, C., & Glenn, S. (2004). Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability. *International Journal of Disability, Development and Education*, 51(4), 335-361.

Abstract

Background: There has been an absence of research exploring the impact of attending further education college on the developing sense of self, among young adults with intellectual disabilities.

Methods: Interpretative Phenomenological Analysis was used to investigate the views and experiences of four young people with intellectual disabilities, using semi-structured interviews.

Results: Analysis identified five superordinate themes: 1) A sense of difference; 2) Being part of it; 3) A changing sense of self; 4) College and new opportunities; 5) I can do it. The transition to college was found to be a positive experience for all participants.

Conclusion: The transition to college was an opportunity for young people to develop their sense of self and their self-identity. Considerations should be given to how young people's sense of self can continue to be supported as they transition into adulthood after leaving college.

Keywords: intellectual disability, identity, self-concept, Interpretative Phenomenological Analysis, college students

Introduction

The British Psychological Association (BPS) state three core diagnostic criteria for a diagnosis of intellectual disability. This includes significant impairment across the three domains of: intellectual functioning, adaptive functioning, and with an onset in childhood (BPS, 2015).

In recent years, Government policies in the United Kingdom have aimed to reduce stigmatisation and promote inclusion of people with intellectual disabilities (UN Convention on the Rights of Persons with Disabilities, 2006; A Fairer Scotland for Disabled People, 2016; Children and Young People Scotland Act, 2014). One means of promoting inclusion is through offering young people with intellectual disabilities opportunities to attend mainstream educational settings, including further education colleges (Scottish Government, 2020a). Further education colleges offer students the opportunity to prepare for adult life, with a focus on supporting students to work towards employment, independent living, and community participation (SEND Code of Practice: 0 – 25 years, 2014). In Scotland, since 2014, there has been a rise in the number of young people identified as having additional support needs (such as intellectual disabilities) entering further education or employment after leaving school (Scottish Government, 2021). However, despite this increase, students with intellectual disabilities still only account for a relatively small proportion of students in further education; approximately 19% of 16–19-year-olds in further education colleges are identified as having additional support needs, such as intellectual disabilities (SEN support: A rapid evidence assessment, 2017). Despite improvements to inclusion across all levels of mainstream education, existing literature mainly focused on the impact of

young people attending mainstream school. However, there has been much less research concerning the experiences of young people in further education, particularly in Europe (Wagner et al., 2005).

O'Brien et al's (2009) study explored the experiences of individuals with intellectual disabilities, who attended further education within a university setting in the Republic of Ireland. The participants reported this experience to be positive, and described feeling more confident, independent and had greater hopes for their futures through completing the course. The participants also expressed a need for similar opportunities to be made available to more young people with intellectual disabilities. In a UK study, Goode (2007) identified some barriers to inclusion for young people with disabilities in further education environments, by examining the experiences of 20 university students with a variety of disabilities. The main themes from their research were regarding identity, concerns about disclosure of disability status, and feeling unprepared for the transition into higher education. Of particular note was the students desire to "fit-in" with other students; concerns regarding disclosing their disability were expressed, which were linked to previous experiences of feeling disadvantaged due to their disability. Students also reported an awareness of societies negative views towards those with disabilities. Furthermore, research by Mason-Roberts (2020) suggests that building relationships with peers and social stress, appears to be a concern for young people with intellectual disabilities, who attend college. Although limited, the previous findings suggest that access to further mainstream education may afford young people with intellectual disabilities the opportunity for personal development, and may be

regarded as a positive experience for young people. However, barriers to inclusion were also highlighted.

In previous research, young people with disabilities report an awareness at a societal level of the negative attributions towards the label of “disability” (Norwich and Kelly, 2004). This awareness of difference, and of society’s stigmatised views, can have negative consequences on a young person’s developing sense of self (Logeswaran et al, 2018; Ali, King, Strydom, & Hassiotis, 2015), which may continue as they transition into further education settings. Mason-Roberts’ (2020) study demonstrated that young people with intellectual disabilities who attend college, reported a sense of loneliness, fear of stigma and concerns about how they may be perceived by others. The findings suggest past social stressors, such as experiences of bullying may contribute to these feelings. Furthermore, their results also highlighted feeling less-able than their typically-developing peers, through a process of social comparison. Festinger’s Social Comparison Theory (1954), states that an individual’s self-evaluations and sense of self are influenced by their social comparisons with others. The process of making downward social comparisons with less able peers may increase an individual’s sense of self, as they compare themselves more favourably. Whereas making upward social comparisons with more able peers may negatively impact an individual’s sense of self, and may make them more aware of their limitations

However, although there is an awareness of the stigma surrounding the “disability” label, individuals may choose to distance themselves from, and reject, these labels (Finlay and Lyons, 2005; Beart et al, 2005). Research

suggests that having an intellectual disability may not be the defining characteristic for young people, who may place greater importance on other factors, and may choose to identify with other groups (Harter et al., 1998) with whom they feel a sense of belonging, for example: as a supporter of a sports team, or in terms of their sexuality (Smith et al, 2015; Dinwoodie et al, 2020). Social identity theory (Tajfel & Turner, 1979) suggests that identification with an “in-group” can contribute to the development of a positive sense of self.

Attending further education colleges may afford young people with intellectual disabilities the opportunity to develop a different sense of self and to achieve a sense of belonging.

Additionally, transitioning from school to further education gives young people with intellectual disabilities the opportunity to make a similar move to their peers, and offers a sense that their lives are following a more typical trajectory towards adulthood (Caton & Kagan, 2007). This move may also allow young people with intellectual disabilities to take on a new role in society as a “college student”, which may lead to an increase in their quality of life and opportunities available to them in the future (Wolfensberger, 2000).

The transition from school to a mainstream further education college plays an important role in helping students acquire the skills needed to enter society and to live independently in the future (Chen and Chu, 2012). Therefore, it is important to understand young people’s experiences of college, the role this may play in their self-perceptions going forward into adulthood, and their sense of inclusion within college life. The existing literature concerning further education is limited, and tends to have a focus on policy rather than students’

experiences (Corby et al., 2012). However, simply attending a mainstream education setting does not always equate to feelings of inclusion; there are many factors which contribute to feeling genuinely included in the college community such as, the formation of friendships, receiving the right support and being able to participate in all opportunities of life (Enable, 2017). This study aims to add to the gap in previous literature, by exploring young people's experience of moving to further education and its impact on their sense of self and belonging.

Method

2.1 Design

This qualitative study used Interpretative Phenomenological Analysis (IPA), in order to explore participants' experiences of stigma and sense of belonging in a further education setting.

2.2 Participants

A total of five individuals with intellectual disabilities were recruited to take part in the study: four males and one female. However, it became evident that one participant did not have a learning disability and was instead attending the course due to other behavioural and learning difficulties. Therefore, the data from this participant was excluded from the study. The four remaining participants were aged between 18 and 21 years, and were recruited from the same further education college in the West of Scotland. Data collection was attempted over a period of seven months from December 2020 – June 2021, and at this time students were exclusively working from home. All participants had attended specialist schools and were identified by the colleges as having a mild-moderate intellectual disability and to have the expressive and receptive verbal skills to express their views in a semi-structured interview.

Prior to college, all participants attended special schools for individuals with intellectual disabilities. Table 1 outlines the participants' characteristics. In order to protect participants identities, pseudonyms are used throughout.

Table 1:

Characteristics of participants

Variable	Participants (pseudonyms)			
	Thomas	Amy	Kevin	John
Gender	Male	Female	Male	Male
Age (years)	18	20	20	21
Living Situation	At home with parents	At home with parents	At home with parents	At home with parents
Additional Diagnoses	No	No	ASD	ASD
Received support for learning in school	Yes	Yes	Yes	Yes

2.3 Socio-demographic questions and Interview

Socio-demographic: Socio-demographic information was collected about the ages and living situations of the participants. Post code data collected for three of the participants was used to identify the deprivation level of the area where they lived, using The Scottish Index of Multiple Deprivation (SIMD). The SIMD scores the deprivation level of each postcode area across seven domains: income, employment, education, health, access to services, crime and housing (Scottish Government, 2020b). Out of the 5 levels, the participants lived in the most deprived areas (SIMD quintile range: 1 – 2).

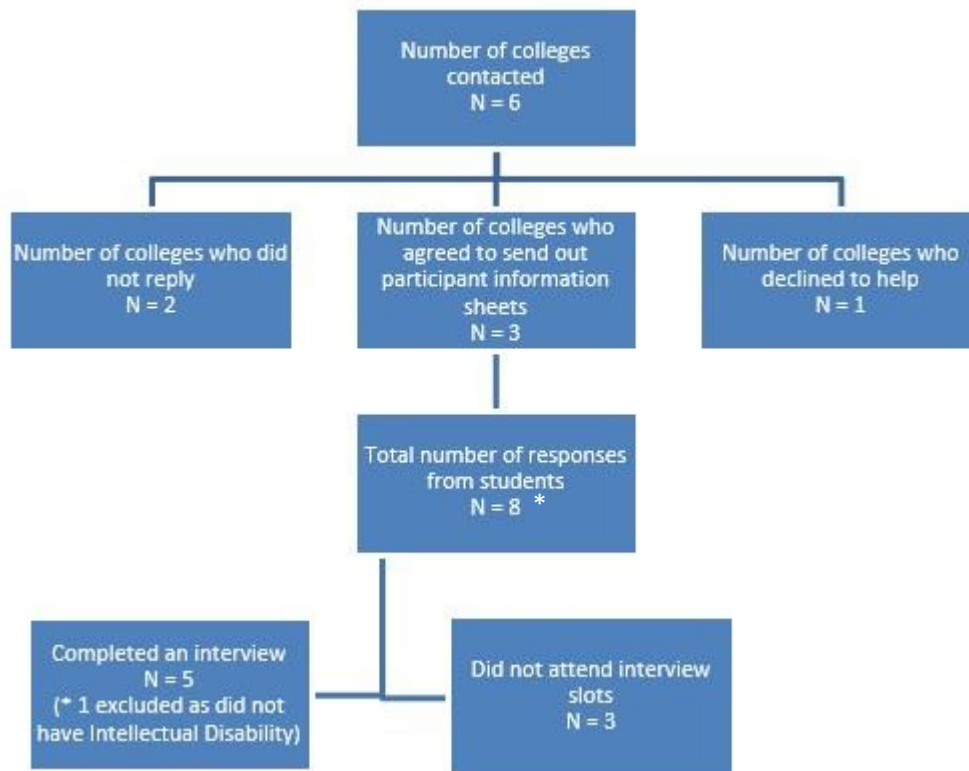
Interview: In keeping with the IPA method, the data was collected through the use of semi-structured interviews, guided by a flexible interview schedule. The interview schedule was developed in collaboration with the research team, in order to capture participants' experiences across a number of topics, including: experience of transition to college, sense of self in relation to peers and siblings,

awareness and experience of stigma, sense of belonging and future aspirations. The interview schedule was designed to be flexible in nature, rather than being rigidly structured. This allowed the participants to expand on topics, or to raise novel issues which had not been considered. The interview began with more general questions concerning the participant's life and their family context, before going onto talk about stigma and inclusion. The aim was to allow the participants become more relaxed and to develop rapport with the researcher, before dealing with more challenging and emotional topics. At the end of the interviews, participants were given the opportunity to discuss any additional topics which they felt were important.

2.4 Procedure

As Figure 1 shows, six colleges in the West of Scotland, who provide Supported Learning courses for students with intellectual disabilities, were contacted and invited to help recruit participants for this study. Of these, three agreed to send out the participant information sheet to their students. The original aim had been to recruit between 6-10 participants. However, the Covid-19 restrictions on physical distancing proved to be a considerable challenge to recruitment. College staff proved to be reluctant to send out the participant information sheet, as they wanted to avoid placing an additional burden on students who they felt were already struggling with remote teaching. In addition to contacting colleges, the researcher also attempted to recruit school leavers through a contact at a special school. However, the students did not reply to the participant information sheet. Thus, despite considerable efforts, it was only possible to recruit 5 participants.

Figure 1: Flow chart indicating the recruitment processes



* N.B. all students who replied to the participant information sheet came from one college.

A participant information letter was sent to the class tutor who then distributed this to potential participants who met the inclusion criteria. Those who were interested in participating were invited to email the researcher directly. In order to ensure participants were able to provide informed consent, a procedure similar to Arscott, Dagnan and Stenfert Kroese (1998) was followed. At the start of each interview, participants were asked if they had read the participant information sheet they had been sent. A verbal overview of the study was presented by the researcher, and participants were asked to verbally respond to each of the statements read out. The researcher determined whether the participants could understand (a) the content of the study, (b) the possible positive and adverse aspects related to participation in the study, (c) that they were aware that they

did not have to participate in the study and could withdraw at any time without providing a reason. If the participant did not understand any of these statements, then the researcher took time to explain them using more accessible language. Informed consent was provided verbally by each participant, and this was recorded separately to the interview.

Due to the physical distancing restrictions in place in Scotland, in order to restrict the spread of COVID-19, interviews were conducted remotely through the use of Microsoft Teams video technology, and lasted approximately 60 minutes. This meant all participants were interviewed in their family homes on a one-to-one basis, at a time which suited them. The interviews were audio recorded, with participants' consent, and were transcribed verbatim. Participant's data was stored in line with Data Protection legislation and the researcher completed a Data Protection Impact Assessment which was reviewed by the University's Data Protection team.

2.5 Analysis

IPA research is underpinned by the principles of hermeneutics and phenomenology, whereby the researcher aims to make sense of how the participants make sense of their particular experiences (Smith et al., 2009). IPA is unique from other qualitative methods, as it explores participants experiences within the context of their personal and wider social worlds. Rather than simply describing the participant's experiences, IPA asks the researcher to use interpretive skills to understand the meaning participants give to their experiences. In order to achieve this, IPA research tends to involve smaller

sample sizes, with participants selected based on their shared experiences on the topic of interest (Rose et al, 2019)

Analysis of the data was carried out by the first author (M.J.) and followed the stages set out by Smith and Osborn (2008). The first stage of analysis involved the reading and re-reading of the transcript, alongside listening back to the recorded interviews. This allowed the researcher to immerse herself in the data and to become more familiar with the content of the interviews. Secondly, the transcriptions were read through line-by-line. This allowed for the identification of interesting or significant points raised during interview from a descriptive, linguistic and conceptual aspect. Third, the transcript and initial notes were reread by the researcher to allow for emergent themes and relevant quotes to be identified. Once identified, a schematic of emerging themes was created for each participant.

At the fourth stage, themes which were identified as connected were grouped into superordinate themes and subthemes, and were given a descriptive label. At this stage, the groups of themes were shared, discussed and agreed upon with the research team. A narrative summary was also completed for each of the participants. This helped to ensure that the researcher kept the analyses grounded in the context of the individual's complete narratives, in line with the IPA ethos of understanding the experiences in the broader context of their lives. These stages were repeated for all four of the transcripts, after which superordinate themes were discussed by the research team. These themes were then compiled into a master theme list which was used for writing up the results. Throughout these stages, all key decisions were recorded and care was taken to ensure that the final themes were rooted in the views participants expressed.

In addition to the above, the researcher was aware of their own position in relation to the research; particularly their personal views which were shaped through experiences of supporting young people with intellectual disabilities in a school context. This could have led to the researcher bringing their own implicit biases or associations about experiences of young people with intellectual disabilities to the data analysis. In order to mitigate these impacts, the researcher kept a reflective diary and engaged in reflective discussions with the research supervisor.

2.6 Ethical considerations

Ethical approval for this study was obtained from the University of Glasgow College of Medicine, Veterinary and Life Sciences Ethics Committee (Appendix 2.4).

Results

The analysis identified four superordinate themes (A. A Sense of Difference; B. Being Part of It; C. A Changing Sense of Self; D. College and New Opportunities, and E. I Can Do It) and 12 subthemes which are outlined further in Table 2. The themes are discussed and are supported by verbatim quotes from participants.

(...) indicates that some text has been omitted, and words enclosed in []

brackets indicate that words have been inserted.

Table 2: Outline of Superordinate and subthemes identified through data analysis

Master Table of Themes and Subthemes for the Group	
A. “They don’t fully understand what my school was like”: A sense of difference	
<ul style="list-style-type: none"> • Experience of stigma in the community • Experience of stigma within school • Friendships and solidarity with peers 	
B. “It was great! I felt like I wasn’t left out anymore”: Being part of it	
<ul style="list-style-type: none"> • Within the school context • Within the college context 	
C. “When I go to college, it’s a completely different set of confidence”: A changing sense of self	
<ul style="list-style-type: none"> • Sense of self at school • Sense of self at college 	
D. “It’s given me so many benefits”: College and new opportunities	
<ul style="list-style-type: none"> • Academic demands • Ethos/culture • Hopes for the future 	
E. “It’s just a disability... but I rise back”: I can do it	
<ul style="list-style-type: none"> • Hopes for the future 	
<ul style="list-style-type: none"> • Potential barriers 	

3.1 “They don’t fully understand what my school was like”: Experiences of Stigma and Awareness of Difference.

Across interviews, it became clear that many participants had experiences of stigma which needed to be understood in the context of their individual social histories.

Whilst all participants placed great value in social relationships with peers, many participants acknowledged that social interaction with others was something they had found difficult. These difficulties tended to be explained in the context of individual difficulties: “I wasn’t that sociable; I didn’t have that many [friends]”, and within the context of experiences of bullying or stigmatisation by peers from both within and outwith the school environment. For example, Thomas* describes experiencing stigma within his local community and spoke about the emotional impact this had on him.

“Yeah, there’s been comments like... [pause] like, there was one example of “mongo”. Someone asked me if I went to a “mongo school”, and I didn’t really want to say “yes” because I didn’t want to be humiliated in a way. So, I just, I kinda (sic) avoided it, and avoided the answer. I wasn’t trying to be in denial, I just tried to avoid the answer.”

(Thomas)

It is clear that these comments provoked a strong emotional reaction from Thomas. He described feeling “humiliated”, perhaps implying these comments triggered a sense of shame regarding having an intellectual disability and the school which he attended.

Experiences of stigma were also reported within special educational schools, by Amy*. In addition to verbal bullying, Amy reported regular experiences of physical bullying at the secondary school she attended.

“I was kinda (sic) often getting bullied... [pause]... One time someone came and tripped me up, and scarred my knee really badly. It bled (sic), now I’m stuck with a scar for life.”

(Amy)

It appears Amy found it difficult to discuss these incidents of bullying; she “preferred not to say”. It was clear, however, that the incidents of bullying appear to have had a lasting impact on Amy, leaving both physical and perhaps emotional scars which she described as “tearing her apart”. Thomas suggested that the bullies were unaware of the benefits that special schools provided to their pupils and wider community:

“It would make me feel down, and also like I didn’t want to be in that school. And that’s why my thoughts keep running constantly that like, I was thinking maybe they are right. But they don’t fully understand what my school was like in a way... Like what happens in my school, as well as giving us support, like they do things for charity and swim galas. The things I appreciate are my pals, the things that I studied and basically the generosity of it.”

(Thomas)

Despite the fact that Thomas appreciated his school, its ethos, and the opportunities it afforded him, other people's stereotyped views made him feel ambivalent about being there. However, he was able to reject people's views as being due to their ignorance. Examining the experiences of stigma in the wider context of participant's lives, these difficult experiences appeared to allow students to form shared bonds with other pupils who faced similar experiences, as Amy explained:

"As soon as I hit S4, and it was one of the assemblies, and she told me about her past and her getting bullied herself. That's when I realised, I shouldn't be mad at this girl because she must have lived the same experience as I did and I shouldn't let that get the better of me."

(Amy)

Consequently, it appears these shared experiences were a unifying bond and there is a sense of finding solidarity with peers who may have also experienced similar stigmatising experiences or who face similar challenges.

In summary, there seems to be a convergence between Amy and Thomas's experiences. This theme highlighted the widespread experiences of bullying and stigma, both from within the school environment and in the wider community. Although the topic of stigma was not directly raised by participants, this became evident through how they described that their school was perceived by others. These experiences left a longstanding emotional and physical impact on the participants, which had impacted their sense of self and feelings of "humiliation". However, a theme of solidarity with peers emerged, and the shared experiences of stigma evoked sympathy amongst peers. As a result of these experiences, the

participants appeared to communicate a sense of social isolation from, and a feeling of difference within, their communities.

3.2 “It was great! I felt like I wasn’t left out anymore”: Sense of Belonging

A sense of belonging appeared to be important to participants, and their transitions to college appeared to have directly impacted this. All participants described their sense of belonging as changing over time, and described feeling a greater sense of belonging in the college environment when compared to school experiences, despite all having attended special schooling. John explained:

“Erm, I don’t know erm, like, I guess it was kinda (sic) hard to fit in [at school], but that’s kind of normal [pause]... I don’t know, I think because I’m less sociable and there’s lots of people and it can be hard to keep up with everyone... I feel I fit in better [at college]. [Long pause] Like at school there were a lot of people in the class and, I don’t know, I think it’s easier to get to know more people because the class is smaller. I just kinda (sic) feel like... I just feel like I fit in well now.”

(John*)

John appears to have felt overwhelmed by the social demands of being in large groups of people at school and appears to have experienced social isolation. However, he described feeling that he fitted in better at college and attributed this to smaller class sizes which may have made social interactions easier for him. Interestingly, this experience diverges from Kevin’s*, who explained the advantages of having more people to speak to at college, rather than less:

“I feel like I fit in a lot more [at college] than school. Like there’s a lot, like [long pause] there’s a lot more people to talk to if I wanted to [long pause], like so I don’t feel like the odd one out or people I could talk to... See because obviously I’m gay, I have a lot of people that would name call because of that [pause]. So, I had to deal with a lot of that in high school and that’s why I felt like the odd one out.”

(Kevin)

Kevin described stigmatising experiences at school related to his sexuality. He attributed these experiences to creating a sense of difference, and lack of belonging with peers. However, he explained that college was a more inclusive environment where he felt able to socialise with classmates who liked him, without fear of discrimination or rejection. Thomas also reported a greater sense of belonging at college:

“Yeah, I’d definitely say I fit in [at college]. It’s not like I feel sheepish when I meet people. Like when I get used to them, I don’t feel sheepish at all, it feels kinda like home, like a foundation. Then, like, when I leave that course and I get into a mainstream course I can start building a new foundation there. I’m looking forward to challenging myself and to making new friends with people I have things in common with and then I can speak to them, like, about troubles and things and academic issues, like if I’m trying to understand a particular concept.”

(Thomas)

Thomas emphasised the importance of interactions with peers in developing his sense of belonging. These peer connections appeared to serve an important function of providing both emotional and academic support for Thomas.

In summary, this theme highlighted shared difficulties with peer interactions which contributed to feelings of social isolation and sense of difference amongst participants. At college, however, participants appeared to have benefited from an increased number of peers to socialise with. Participants seemed to have been able to find their social niches at college; social groups which share their interests and with whom they can identify.

3.3 “When I go to college, it’s a completely different set of confidence”:

Self-identity Changing over Time

When the participants made the transition to college, they reported experiencing a greater feeling of acceptance among peers, and felt they were able to find their own social niche. All four of the participants described a sense of change over time in how they perceived themselves; recounting a sense of personal growth and development since attending college. Thomas described the following changes:

“Like getting to walk into college, getting to take the bus over to college because, like I used to wait on a bus that would come to me; but now, like,

I have to go to a bus to go to college... It's going brilliant. It's without doubt the best experience. It's also a sign of stress relief... like when I'm walking, it will blow the majority of stress away from when I'm at home... when I get a bus or walk to college it makes me feel more confident, more confident... When I go to college it's a completely different set of confidence, so in a way of let's just say bravery... like it makes me feel like I'm more responsible."

(Thomas)

Thomas indirectly described how his sense of self had changed since transitioning to college, through independent travel. He noted benefits to his emotional wellbeing as well as a greater sense of belief within himself, and appeared to have fostered a sense of self-pride. Kevin's experience also echoed this change over time:

"erm like, I'm more, at school I wasn't really myself, but now I'm like "I don't care"; I'll just be myself and that's fine and if someone has something to say... [long pause]"

(Kevin)

Kevin described a lack of congruence between the image he held of himself privately, and the person portrayed at school for peer acceptance. He explained how he developed a greater sense of self-acceptance since transitioning to college, and reported being able to be himself at college. Amy also reported a changing sense of self identity:

[At school] “Well, I actually started changing in a way when I hit S4 I started crying less and less... I was either overreacting or people not bullying me anymore... I felt that people are finally understanding what I’m saying... it makes me feel really happy”. [At college] “Well, I get to buy my own food and I can go wherever I want... It’s good... because... I’m allergic to so many dairy products... but I’m able to choose what I eat. More choices.”

(Amy)

Similarly, Amy reported a greater sense of acceptance and responsibility since transitioning to college which appeared to have a positive impact on her sense of self and allowed for her to have increased empowerment over her physical health and take responsibility for her dietary needs.

In summary, this theme has highlighted participants perceived positive development of their identity, when they made the transition from school to college. All of the participants experiences appear to converge, as they described greater independence, greater sense of responsibility and an increase in self-confidence since attending college. They also highlighted a sense of self-acceptance and a feeling of being understood by peers which has added to their enjoyment of college and personal growth.

3.4 “It’s given me so many benefits”: Transition to College

Across the interviews, all four participants described the many benefits and challenges they experienced since beginning college. These were mainly centred

around college ethos and academic demands. Thomas explained what he enjoys about college:

“I think it’s been great, yes it’s been great. Like the course have built, like, not only a mental structure of how I learn, but generally it’s a good zone for me to make new friends and for me to like, actually start a new era on my life - a new sort of journey for me... It felt new, it felt, it just felt new. It felt like my destiny has taken me into another world for the best, because it’s given me so many benefits.”

(Thomas)

There is a sense that the transition to college offered Thomas a chance at a fresh start and an opportunity to meet new peers and develop more social relationships. For him, acceptance among peers seemed particularly important. It appears Thomas ‘s sense of self may be shaped by how he is perceived by his peers. Therefore, having friendships with others may have enhanced his sense of self or identity, when compared with school experiences. His words also offer a sense of belonging and acceptance which feel important to him. John also described noticing change since attending college:

“It was a bit weird at first, but I kinda got used to it... erm, I think it’s different. I don’t know it just feels different because you’re older than when at school... yeah, I’d say in some ways you get treated differently. They treat you, yeah that’s what I meant about being older, they treat you more like an adult, at school they treat you more like a kid.”

(John)

Despite initial uncertainty, John reported noticing a change in how he is treated by others. John suggested that his sense of self has changed and he now viewed himself as more mature than when at school, and attributed this to being perceived differently by college staff, suggesting that perception of others is important in his developing sense of self. Kevin reported a similar experience:

“Everyone’s an adult and they’re not, [pause] I’d say people younger can be rude and that. Like, in college, everyone is more respectful so I think it’s a better place.”

(Kevin)

Kevin’s experience of college appeared to be a contrast to his school experience, where he reported bullying and stigmatised treatment attributed to his self-identity. Again, Kevin noted the importance of others’ perceptions in his changing sense of self.

Some participants also acknowledged the academic differences encountered at college, and expressed some concerns about their abilities to keep up with the academic demands of their course:

[In relation to starting a mainstream course next academic year] “Maybe about failing, I could worry about. Like for a certain reason, let’s just say maybe it’s because I, like during an exam or so; I could possibly get a lower score and then I’d have to do the course again and that’s what I’m worried about in the future. I’d also be worried about, like the mental health issues in general. Worried that would put me off production... let’s just say for example if I was given work that was incredibly difficult to understand and it took me days to get it done, there would be even more

pressure if they set a deadline on it, like when to give it back and when they expect it to be done... erm, it would probably be a massacre when you think about it.”

(Thomas)

For Thomas, the pressure he felt about the need to pass exams in mainstream classes had wider implications than academics failure. Thomas’ concern about passing his course may also have been important for peer acceptance. The thought of rejection from the cohort provoked an emotional reaction from Thomas, who would consider this a “massacre” in relation to his sense of identity. The transition to college has ramifications for Thomas beyond obtaining an education; it may be an opportunity for Thomas to confirm his belonging in a mainstream community.

The transition to college appears to have provided many benefits and challenges to all participants. Despite some academic difficulties, most reported how greater acceptance among peers and being perceived as more responsible among college staff had a positive impact on their developing sense of self and identity. There appeared to be a sense that this had changed over time since transitioning from school and over the course of their college experiences.

3.5 “It’s just a disability... but I rise back”: Desire to succeed

All participants spoke of their desire to succeed in the future, after college, and in entering employment. Kevin and John each note that they would like to work with computers, but Kevin expressed some uncertainty about how to achieve his goal: “I don’t know how that’s going to work.” Amy noted the sporting avenues that may become available to her through mainstream courses:

“And finally, not only get my mainstream course, if I can get this mainstream course, I can help my team get in the mainstream action and we will be up against the Australians [netball team] soon.”

(Amy)

Amy explained that the sporting experiences available to her are also dependent on her achieving success in mainstream courses, and this is her driver for the future. Thomas also demonstrates a desire to succeed in his future:

“Like it [having an intellectual disability] holds me back in life sometimes in the learning perspective, but then the plan [plan for his future]? It could affect both in a way, it could affect both, but it’s not as strong, it’s just a disability that kinda (sic) holds me down but I rise back up after that. It’s just the way life is. You’re not born with intelligence, you build that; you build that intellect.”

(Thomas)

This extract highlights the impact of intellectual disability on young people’s futures. Thomas demonstrates defiance of this and a determination to succeed in spite of his difficulties. His language implied an ongoing battle and that he will

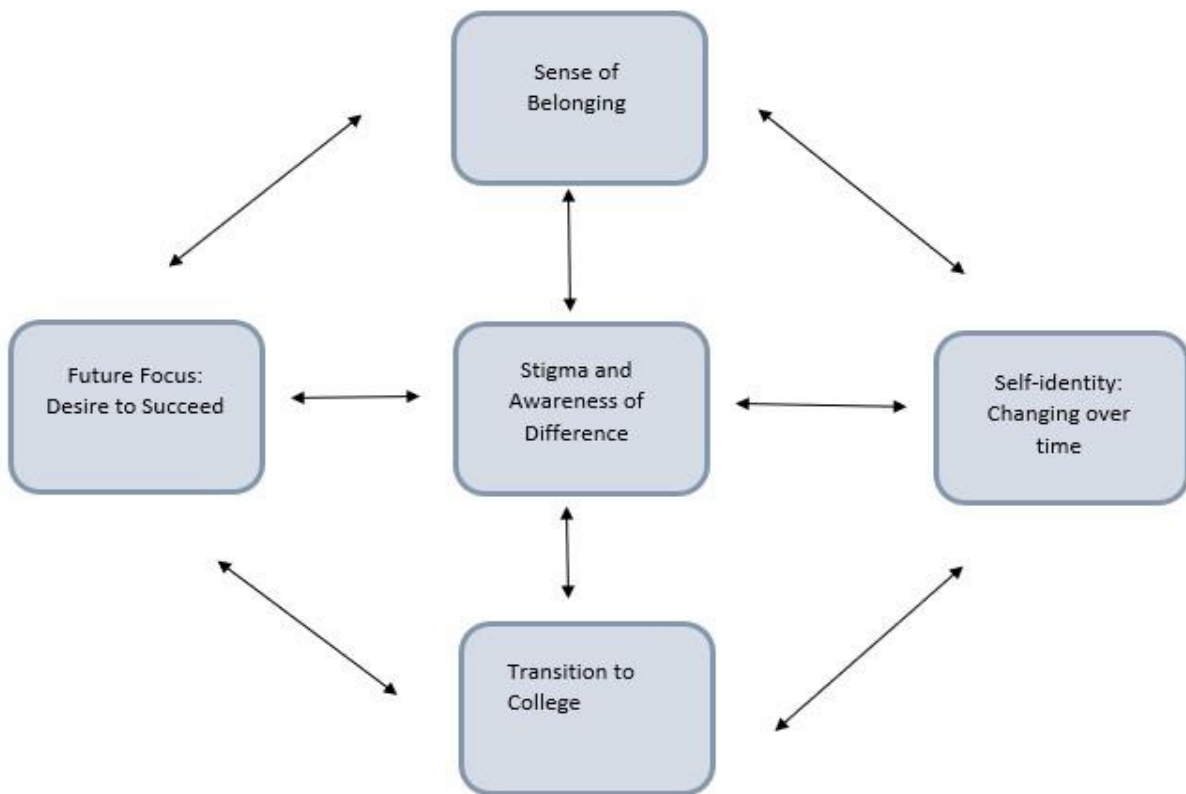
persevere to achieve his goals, demonstrating a degree of resilience in face of stigma. It also appears important for Thomas to present himself as able. He appears to distance himself from the label of intellectual disability, and appears to identify with more able peers.

These extracts highlight the systemic barriers which young people with intellectual disabilities face due to their status as having an intellectual disability. Despite an awareness of these barriers, however, the participants all describe a strong desire to succeed and achieve their goals. Interestingly, participants appeared to define their identities and future identities in terms of their achievements and what they hope to be able to achieve, rather than their disabilities. This suggests that disability may not always be a defining component of their self-identities.

Discussion

This study established a detailed account of the experiences of four young people with mild intellectual disabilities, who attend college, and the impact of these on their sense of belonging in the college environment and on their sense of self. The narrative which emerged through the analysis points to a complex interplay between past experiences of stigma, sense of belonging, self-identity, college experiences and future goals, all of which appear to be multidimensional in nature and changing over time as the participants transition from school pupils into adulthood. The relationships between these themes has been drawn out in Figure 2 and demonstrates the interesting relationship between the themes:

Figure 2: Schematic demonstrating the relationships between the five themes



All four of the study participants attended special educational schools. However, it is interesting that all participants were positive about their experiences of specialist schooling. Two participants reported that negative life experiences such as stigmatisation or bullying had a negative impact on how they viewed themselves in relation to others without disabilities. However, two participants did not report experiencing bullying or an awareness of being viewed as different due to attending a special school. This is interesting, as previous research has found that young people with intellectual disabilities have an awareness of societal stigma towards people with intellectual disabilities (Norwich and Kelly, 2004). Experiencing stigma can be a distressing, and it may have been that participants did not wish to discuss this emotive topic

during the interview. Moreover, individuals with intellectual disabilities can be socially isolated (Friedman and Rizzolo, 2018), and it is possible that some participants may not have experienced bullying or discrimination simply because of a lack of contact with peers in their community.

Interestingly, all participants reported difficulties with peer interactions at their special schools. Participants noted that this contributed to them feeling “left-out” and seeking friendships with individuals who shared their interests (Friedman and Rizzolo, 2018; Giesbers et al, 2018). In addition to a diagnosis of intellectual disability, two of the participants also had diagnoses of autism spectrum disorder. Difficulties with social interactions can be a key characteristic of autism (Friedrich et al., 2015), and research suggests higher rates of social anxiety and social avoidance among young people with autism (Kuusikko et al., 2008). However, despite reporting social difficulties at school, these two participants reported that their social interactions with peers had improved at college, and they reported enjoying the social aspect of college life; this fostered a sense of belonging in the college environment. These findings may challenge the previous assumptions regarding the social preferences of young people with autism (Kuusikko et al., 2008).

Overall, the participants reported the transition from school to college as a positive experience, and all participants appeared to view this transition as an opportunity to develop greater independence, to learn new skills and develop their own identities. For example, Kevin spoke about being able to develop his sexual identity, which is in line with previous literature (Dinwoodie et al, 2020; Smith et al, 2015). Although all participants acknowledged their learning disabilities, this did not appear to be a defining aspect of their sense of self. These

findings are interesting, and appear to be in line with previous literature which describes the multi-faceted nature to the development of self-perception (Harter et al., 1998). The transition to college appears to have positively impacted participants sense of self, as they reported feeling more grown-up, confident and responsible than when compared to school. Participants appeared to have used the opportunity of attending college to find their own sense of identity and felt more included in the college community.

Finally, the study participants reported hope and optimism about their futures. These findings are in line with previous research which suggests students with intellectual disabilities felt equally as likely to achieve their future goals, as their non-disabled peers, and were optimistic about their futures (Cooney et al., 2006). All participants described their future goals, and how they would like their life to look. All participants expressed a desire to enter employment upon leaving college, and explained that college was a stepping-stone towards achieving this goal by providing access to courses which would specifically prepare them for their work goals. When discussing life after college, these young people expressed a sense that leaving college would signal a transition into adult life; which may perhaps lead to continued development of identity as they hope to become employees, colleagues and included members of society.

4.1 Study Limitations

The main limitation of this study is the relatively small sample size, and recruitment for this study may have been negatively impacted by the physical distancing restriction in place to limit the spread of COVID-19. Although it is not

expected that qualitative findings of this nature will be generalisable, a larger sample size would have allowed for a greater understanding of people's views and experiences of transitioning to college. It would have been particularly beneficial to hear about the experiences of individuals from different colleges to see if this may have influenced their view of the transition. However, Smith and Osborn (2008) have proposed that a smaller sample size of even three may allow for greater depth of analysis and help to prevent a novice researcher from being overwhelmed by the volume of data.

In addition, the recruitment and interview method may have potentially led to a biased sample; whereby those who may have had a positive college experience, a better relationship with their college tutor, greater self-confidence to volunteer for the study, or had access to technology, may have been more likely to volunteer to take part in the study. It is possible that these findings may not represent all student experiences.

An additional limitation of this study was the inability to administer even a brief measure of cognitive functioning, such as the two-subtest form of the Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-11; Wechsler, 2011). The participants' intellectual disability status was confirmed by the college tutor after careful explanation by the researcher. However, researchers have suggested that education services can often confuse intellectual disability with specific learning difficulties, such as dyslexia or dyspraxia (Brougham, Pert, Jahoda, 2020). Previous studies have reported facing difficulties with identifying and recruiting participants with intellectual disabilities from colleges (Mason-Roberts, 2020). Although half of the participants specifically referred to their

intellectual disability during the interviews, and all participants included in the analysis had attended specialist schools for individuals with an intellectual disability, the absence of confirmatory data about the level of their cognitive functioning remains a weakness of the study.

4.2 Implications and future research

This study highlighted the perceived benefits of access to further education.

The transition to further education college appeared to have been an important step in developing their own sense of self. However, the number of young people with intellectual disabilities progressing to further education colleges reduced in recent years (Scottish Government, 2021). Further research on this topic might help to provide evidence to underpin future decision making about whether access to college should be expanded for this group of young people.

All participants were enrolled on a “Steps to Employability” college course, with the purpose of finding employment after completing their course. However, it remains uncertain if the positive aspirations for the future, reported by the young people in the study, will be realised. Previous research has suggested that, despite employment having a positive impact on social status (Jahoda et al, 2009) and subjective quality of life (McCorry et al, 2014) for individuals with intellectual disabilities, there continue to be few work opportunities available (McCausland et al, 2020). Recent statistics suggest that only 17% of all adults with an intellectual disability in England, are in paid employment (Emerson and Hatton, 2008); compared to 76% of the general population in England (ONS, 2019). The UN convention on the rights of persons with disabilities (2006) outlines that all individuals should be able to participate fully in society,

including access to education and employment. It would be important for future research to explore employment and transition to adulthood for people with intellectual disabilities, and the impact of unemployment on their self-perceptions.

4.3 Conclusion

Overall, this study suggests that young people with intellectual disabilities view the transition to college as a positive experience, and one which had contributed to the development of their sense of self. These young people felt that their confidence and skills had improved in further education. This provides support for the practise of promoting more inclusive opportunities for young adults with intellectual disabilities, in line with Government policies (A Fairer Scotland for Disabled People, 2016).

References

- Akin, D., & Huang, L. M. (2019). Perceptions of College Students with Disabilities. *Journal of Postsecondary Education and Disability*, 32(1), 21-33.
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self-stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in developmental disabilities*, 33(6), 2122-2140.
- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England. *Journal of Affective Disorders*, 187, 224-231.
- Arcott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of applied research in intellectual disabilities*, 18(1), 47-56.
- British Psychological Society (2015) *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. BPS Publication. Online <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Guidance%20on%20the%20Assessment%20and%20Diagnosis%20of%20Intellectual%20Disabilities%20in%20Adulthood.pdf> [last accessed 23.09.2021].
- Brougham, L, Pert, C, & Jahoda, A. (2020) Exploring the ability of individuals with an intellectual disability to generate and use a compassionate image. *Journal of Applied Research in Intellect Disability*. 00, 1– 11.
- Chen, C. H., & Shu, B. C. (2012). The process of perceiving stigmatization: Perspectives from Taiwanese young people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25(3), 240-251.

- Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, 50(6), 432-444.
- Cunningham, C., & Glenn*, S. (2004). Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability. *International Journal of Disability, Development and Education*, 51(4), 335-361.
- Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, 43(5), 372-379.
- Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social–cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, 11(4), 247-254.
- Damon, W., & Hart, D. (1991). *Self-understanding in childhood and adolescence* (No. 7). CUP Archive.
- Deakin, K., Moore, D. G., & Jahoda, A. (2017). Children and young people with Down syndrome: Their awareness of Down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1197-1208.
- Dinwoodie, R., Greenhill, B., & Cookson, A. (2020). ‘Them two things are what collide together’: Understanding the sexual identity experiences of lesbian, gay, bisexual and trans people labelled with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(1), 3-16.
- Elliott, S. and Stanton, A. (2019, August 21) “Edinburgh’s disabled children being “segregated” in mainstream schools due to lack of support. *The Edinburgh News*
<https://www.edinburghnews.scotsman.com/news/people/edinburghs-disabledchildren-being-segregated-mainstream-schools-due-lack-support-542392> (last accessed 19.07.2021)

Emerson, E. & Hatton, C. (2008). People with Learning Disabilities in England. Centre for Disability Research.

European Commission (2019) Special education needs provision within mainstream education. https://eacea.ec.europa.eu/national-policies/eurydice/content/special-education-needs-provision-within-mainstreameducation-79_en (last accessed 19.07.2021).

Festinger L. (1954) A theory of social comparison processes. *Human Relations* 7, 117-1140

Finlay, W. M., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39(1), 129-146.

Finlay, W. M., & Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation*, 43(2), 120-134.

Friedman, C., & Rizzolo, M. C. (2018). Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 30(1), 39-54.

Friedrich, E. V., Sivanathan, A., Lim, T., Suttie, N., Louchart, S., Pillen, S., & Pineda, J. A. (2015). An effective neurofeedback intervention to improve social interactions in children with autism spectrum disorder. *Journal of autism and developmental disorders*, 45(12), 4084-4100.

Giesbers, S. A., Hendriks, L., Jahoda, A., Hastings, R. P., & Embregts, P. J. (2019). Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 446-456.

Goffman, E. (1963; 1990). *Stigma: notes on the management of spoiled identity*. England; Penguin.

Harter, S. (1999). The construction of the self: A developmental perspective. New York: Guilford Press

Jahoda, A., Banks, P., Dagnan, D., Kemp, J., Kerr, W., & Williams, V. (2009). Starting a new job: The social and emotional experience of people with

intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(5), 421–425

Jahoda, A. and Wilson, Alastair and Stalker, K. and Cairney, A. (2010) Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719-729.

Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A. S., Mattila, M. L., Ebeling, H., ... & Moilanen, I. (2008). Social anxiety in high-functioning children and adolescents with autism and Asperger syndrome. *Journal of autism and developmental disorders*, 38(9), 1697-1709.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 27(1), 363-385.

Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 533-542.

Martlew, M., & Hodson, J. (1991). Children with mild learning difficulties in an integrated and in a special school: comparisons of behaviour, teasing and teachers' attitudes. *British Journal of Educational Psychology*, 61(3), 355-372.

McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2020). In pursuit of meaningful occupation: Employment and occupational outcomes for older Irish adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 386-397.

McCrory, C., Leahy, S., & McGarrigle, C. (2014). *What factors are associated with change in older people's quality of life?* In A. Nolan, C. O'Regan, C. Dooley, D. Wallace, A. Hever, H. Cronin, E. Hudson, & R. A. Kenny (Eds.), *The over 50s in a changing Ireland: Economic circumstances, health and wellbeing*. 153-183. Dublin, Ireland: The Irish Longitudinal Study on Ageing.

Norwich, B., & Kelly, N. (2004). Pupils' views on inclusion: moderate learning difficulties and bullying in mainstream and special schools. *British educational research journal*, 30(1), 43-65.

O'Byrne, C., & Muldoon, O. (2017). Stigma, self-perception and social comparisons in young people with an intellectual disability. *Irish Educational Studies*, 36(3), 307-322.

ONS (2019b) Labour market overview, UK: May 2019 (Statistical Bulletin). URL: <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/uklabourmarket/april2019> (last accessed 25.07.2021)

Rose, J., Malik, K., Hirata, E., Roughan, H., Aston, K., & Larkin, M. (2019). Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities?. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1007-1017.

Scottish Government (2016) A Fairer Scotland for Disabled People. *Local Government and Communities Directorate*
<https://www.gov.scot/publications/progress-report-fairer-scotland-disabledpeople/#:~:text=In%202016%20Scottish%20Government%20launched%20A%20Faire%20Scotland,real%20transformational%20change%20for%20disabled%20people%20across%20Scotland.> (last accessed: 25/07/2021)

Scottish Government (2014) Children and Young People Scotland Act. *Department for Health and Social Care*
<https://www.gov.scot/publications/childrenyoung-people-scotland-act-2014-national-guidance-part-12/#:~:text=%20Children%20and%20Young%20People%20%28Scotland%29%20Act%202014%3A,the%20last%20ten%20years%2C%20the%20Scottish...%20More%20> (last accessed: 25/07/2021)

Scottish Government (2020a) Standards in Scottish Schools etc. Act
Department for Education: <https://www.legislation.gov.uk/asp/2000/6/contents>
(last accessed: 25/07/2021).

Scottish Government (2020b) Scottish Index of Multiple Deprivation 2020,
Department of Housing and Social Justice

<https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/>

(last accessed 27/07/2021)

Scottish Government (2021) Summary Statistics for Follow-up Leaver

Destinations, No. 3: 2021 Edition, Department for Education:

[https://www.gov.scot/publications/summary-statistics-follow-up-](https://www.gov.scot/publications/summary-statistics-follow-up-leaverdestinations-no-3-2021-edition/pages/3/)

[leaverdestinations-no-3-2021-edition/pages/3/](https://www.gov.scot/publications/summary-statistics-follow-up-leaverdestinations-no-3-2021-edition/pages/3/) (last accessed: 25/07/2021).

Smith J. A. & Osborne M. (2008) Interpretative phenomenological analysis. In: Qualitative Psychology: A Practical Guide to Research Methods, 2nd edn. (ed Smith J.) pp. 53–80. Sage, London.

Smith, J.A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. SAGE, London.

Smith, L., Wedgwood, N., Llewellyn, G. M., & Shuttleworth, R. (2015). Sport in the lives of young people with intellectual disabilities: Negotiating disability, identity and belonging.

Tajfel, H., Turner, J. C., Austin, W. G., & Worchel, S. (1979). An integrative theory of intergroup conflict. *Organizational identity: A reader*, 56(65), 9780203505984-16.

Tickle, Louise (2019, May 7) “Cleansed by cute”: schools refuse places to special needs pupils. *The Guardian*

<https://www.theguardian.com/education/2019/may/07/cuts-heads-refuseschool-places-pupils-special-needs> (last accessed 19.07.2021).

Vignes, C., Godeau, E., Sentenac, M., Coley, N., Navarro, F. Grandjean, H.

2009. Determinants of students’ attitudes towards peers with disabilities.

Developmental Medicine & Child Neurology, 51: 473–479.

Weschler, D (1999) Weschler Abbreviated Scale of Intelligence – two subtest.

Pearson Clinical

United Nations (2006). Convention on the rights of persons with disabilities. New York, NY: United Nations.

Appendices

Appendix One: Systematic Review

1.1 Journal author guidelines

Extract from author guidelines JARID. Full guidelines available at:

<https://www.onlinelibrary.wiley.com/page/journal/14683148/homepage/forauthors.html>

PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as “retarded”, “handicapped”, or “mentally handicapped”. Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., “autistic people”) or person-first language (e.g., people with autism”), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as “ID” or “LD”. Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

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.**

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

Title page

The title page should contain:

- i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));
- ii. A short running title of less than 50 characters;
- iii. The full names of the authors;
- iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- v. Acknowledgments.

Authorship

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

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

Database: British Education Index (EBSCOhost)

Search Date: 24/05/2021

Retrieved Records: 32

<input type="checkbox"/>	S11	 S3 AND S4 AND S9	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S10	 S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S9	 S5 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S8	 S6 NOT S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S7	 TI "peer review" OR AB "peer review"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S6	 TI peer# OR AB peer#	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S5	 TI (((social* N1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*))) OR AB (((social* N1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*)))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S4	 TI (((school* or education) N2 (mainstream* or special*))) OR AB (((school* or education) N2 (mainstream* or special*)))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S3	 S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S2	 TI down* syndrome OR AB down* syndrome	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S1	 TI (((mental* or intellectual* or learning) N1 (disab* or disorder* or deficien* or retard*))) OR AB (((mental* or intellectual* or learning) N1 (disab* or disorder* or	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

Database:

Ovid MEDLINE® and in-process, In-Data-Review & Other Non-Indexed

Citations 1946 to May 24, 2021

Search Date: 24/05/2021












Retrieved Records: 145



Searches

<input type="radio"/>	1	exp intellectual disability/
<input type="radio"/>	2	((mental* or intellectual* or learning) adj1 (disab* or disorder* or deficien* or retard*)).tw.
<input type="radio"/>	3	down* syndrome.tw.
<input type="radio"/>	4	1 or 2 or 3
<input type="radio"/>	5	Mainstreaming, Education/
<input type="radio"/>	6	((school* or education) adj2 (mainstream* or special*)).tw,kw,sh.
<input type="radio"/>	7	5 or 6
<input type="radio"/>	8	4 and 7
<input type="radio"/>	9	(social* adj1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*)).tw,kw.
<input type="radio"/>	10	exp peer group/
<input type="radio"/>	11	peer?.tw.
<input type="radio"/>	12	"peer review".tw.
<input type="radio"/>	13	11 not 12
<input type="radio"/>	14	9 or 10 or 13
<input checked="" type="radio"/>	15	8 and 14

Database:
 PSYCHInfo
 Search Date: 24/05/2021
 Retrieved Records: 399

<input type="checkbox"/>	S11	 S3 AND S4 AND S9	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S10	 S3 AND S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S9	 S5 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S8	 S6 NOT S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S7	 T1 "peer review" OR AB "peer review"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S6	 T1 peer# OR AB peer#	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S5	 T1 (((social* N1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*))) OR AB (((social* N1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*)))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S4	 T1 (((school* or education) N2 (mainstream* or special*))) OR AB (((school* or education) N2 (mainstream* or special*)))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S3	 S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S2	 T1 down* syndrome OR AB down* syndrome	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
<input type="checkbox"/>	S1	 T1 (((mental* or intellectual* or learning) N1 (disab* or disorder* or deficien* or retard*))) OR AB (((mental* or intellectual* or learning) N1 (disab* or disorder* or deficien* or retard*)))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

Database:

EMBASE 1947 – present, updated daily

Search Date: 24/05/2021 Retrieved Records: 325

<input type="checkbox"/>	# ▲	Searches
<input type="checkbox"/>	1	exp intellectual disability/
<input type="checkbox"/>	2	((mental* or intellectual* or learning) adj1 (disab* or disorder* or deficien* or retard*)),tw.
<input type="checkbox"/>	3	down* syndrome.tw.
<input type="checkbox"/>	4	1 or 2 or 3
<input type="checkbox"/>	5	Mainstreaming, Education/
<input type="checkbox"/>	6	((school* or education) adj2 (mainstream* or special*)),tw,kw,sh.
<input type="checkbox"/>	7	5 or 6
<input type="checkbox"/>	8	4 and 7
<input type="checkbox"/>	9	(social* adj1 (compar* or interaction* or perception* or accept* or approv* or conform* or adjust* or understand* or identit*)),tw,kw.
<input type="checkbox"/>	10	exp peer group/
<input type="checkbox"/>	11	peer?.tw.
<input type="checkbox"/>	12	"peer review".tw.
<input type="checkbox"/>	13	11 not 12
<input type="checkbox"/>	14	9 or 10 or 13
<input type="checkbox"/>	15	8 and 14

JBI CRITICAL APPRAISAL CHECKLIST FOR ANALYTICAL CROSS SECTIONAL STUDIES

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the exposure measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were objective, standard criteria used for measurement of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were confounding factors identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were strategies to deal with confounding factors stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

EXPLANATION OF ANALYTICAL CROSS SECTIONAL STUDIES CRITICAL APPRAISAL

How to cite: Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis*. JBI, 2020. Available from <https://synthesismanual.jbi.global>

Analytical cross sectional studies Critical Appraisal Tool

Answers: Yes, No, Unclear or Not/Applicable

1. Were the criteria for inclusion in the sample clearly defined?

The authors should provide clear inclusion and exclusion criteria that they developed prior to recruitment of the study participants. The inclusion/exclusion criteria should be specified (e.g., risk, stage of disease progression) with sufficient detail and all the necessary information critical to the study.

2. Were the study subjects and the setting described in detail?

The study sample should be described in sufficient detail so that other researchers can determine if it is comparable to the population of interest to them. The authors should provide a clear description of the population from which the study participants were selected or recruited, including demographics, location, and time period.

3. Was the exposure measured in a valid and reliable way?

The study should clearly describe the method of measurement of exposure. Assessing validity requires that a 'gold standard' is available to which the measure can be compared. The validity of exposure measurement usually relates to whether a current measure is appropriate or whether a measure of past exposure is needed.

Reliability refers to the processes included in an epidemiological study to check repeatability of measurements of the exposures. These usually include intra-observer reliability and interobserver reliability.

4. Were objective, standard criteria used for measurement of the condition?

It is useful to determine if patients were included in the study based on either a specified diagnosis or definition. This is more likely to decrease the risk of bias. Characteristics are another useful approach to matching groups, and studies that did not use specified diagnostic methods or definitions should provide evidence on matching by key characteristics

5. Were confounding factors identified?

Confounding has occurred where the estimated intervention exposure effect is biased by the presence of some difference between the comparison groups (apart from the exposure investigated/of interest). Typical confounders include baseline characteristics, prognostic factors, or concomitant exposures (e.g. smoking). A confounder is a difference between the comparison groups and it influences the direction of the study results. A high quality study at the level of cohort design will identify the potential confounders and measure them (where possible). This is difficult for studies where behavioral, attitudinal or lifestyle factors may impact on the results.

6. Were strategies to deal with confounding factors stated?

Strategies to deal with effects of confounding factors may be dealt within the study design or in data analysis. By matching or stratifying sampling of participants, effects of confounding factors can be adjusted for. When dealing with adjustment in data analysis, assess the statistics used in the study. Most will be some form of multivariate regression analysis to account for the confounding factors measured.

7. Were the outcomes measured in a valid and reliable way?

Read the methods section of the paper. If for e.g. lung cancer is assessed based on existing definitions or diagnostic criteria, then the answer to this question is likely to be yes. If lung cancer is assessed using observer reported, or self-reported scales, the risk of over- or underreporting is increased, and objectivity is compromised. Importantly, determine if the measurement tools used were validated instruments as this has a significant impact on outcome assessment validity.

Having established the objectivity of the outcome measurement (e.g. lung cancer) instrument, it's important to establish how the measurement was conducted. Were those involved in collecting data trained or educated in the use of the instrument/s? (e.g. radiographers). If there was more than one data collector, were they similar in terms of level of education, clinical or research experience, or level of responsibility in the piece of research being appraised?

8. Was appropriate statistical analysis used?

As with any consideration of statistical analysis, consideration should be given to whether there was a more appropriate alternate statistical method that could have been used. The methods section should be detailed enough for reviewers to identify which analytical techniques were used (in particular, regression or stratification) and how specific confounders were measured.

For studies utilizing regression analysis, it is useful to identify if the study identified which variables were included and how they related to the outcome. If stratification was the analytical approach used, were the strata of analysis defined by the specified variables? Additionally, it is also important to assess the appropriateness of the analytical strategy in terms of the assumptions associated with the approach as differing methods of analysis are based on differing assumptions about the data and how it will respond.

Appendix Two: Major Research Project

Appendix 2.1 - Original Study MRP Proposal

Major Research Project Proposal

Title of Project: The experience of stigma and the perceptions of self and other others by young people with an intellectual disability.

Academic Supervisor: Professor Andrew Jahoda

Abstract

Background: The proposed study aims to explore the experience of stigma, self-concept and perceptions of other young people with Intellectual Disabilities (ID) among college aged students. The aim is to investigate whether stigma experiences impacts on young people's perceptions of self and others. Methods: young people aged between 16 – 25 will be recruited from colleges in the Greater Glasgow and Clyde area. Participants will be supported by the researcher to complete self-report tasks to examine their perceptions of self and others with an intellectual disability and their stigma experiences. A within-subjects analysis will report the descriptive statistics of these measures, and a correlational analysis will explore any relationship between perceptions of self and others, with stigma experiences. Applications: This study will contribute to the theoretical understanding of the relationship between stigma experiences, psychological wellbeing, self-concept and perceptions of others with ID. The results could also be used clinically to better understand and support the mental wellbeing of young people with ID.

Introduction

Individuals with intellectual disabilities (ID) are often negatively affected by stigma (Schalock et al, 2010). Stigmatised treatment occurs when an individual's perceived differences to a group or society result in labelling, stereotyping, separation, loss of status, and discrimination (Link and Phelan, 2001). The label of "intellectual disability" can prove to be a stigmatising one, and perceived as a negative attribute (O'Bryne and Muldoon, 2017; Logeswaran et al, 2018). Stigmatisation can take many forms and can include more overt behaviour such as verbal abuse and rejection, as well as more subtle forms such as restricted opportunities, perhaps from protective family-members (Jahoda

et al, 2010). Research has shown that young people with ID report a higher number of stigmatising experiences due to their ID status (Deakin et al, 2017). These experiences have been shown to have an impact on emotional, social and educational development, with negative consequences for young people with ID's developing selfconcept and mental health (Cunningham and Glenn, 2004).

Research into the experiences of stigmatisation amongst young people with ID has tended to focus on stigma within education settings; comparing the impact of mainstream versus specialist education provision. Within mainstream education settings, Cooney et al's (2006) study found that pupils with an ID reported more abusive treatment from peers than those in specialist educational schools (SES) (Jahoda et al, 2010). Vignes et al (2009) found that young people with Down syndrome and other ID were often the recipients of stigmatised treatment by peers and were less likely to be included in the classroom activities. Whilst Martlew and Hodson (1991), found that young people with ID in a mainstream education setting were significantly more likely to experience bullying and teasing than their non-disabled peers.

It was originally thought that attending a SES may act as a protective factor against the stigmatising experiences of bullying and discriminatory treatment, as spending time with peers of similar abilities may protected children from an awareness of their own limitations and ability levels (Finlay and Lyons, 2000). This view was supported by Festinger's Social Comparison Theory (1954), which states that an individuals' selfevaluations and sense of self are influenced by their social comparisons with others. However, research has found evidence of stigmatising treatment and awareness of difference among young people attending SES. Norwich and Kelly (2004) found that both pupils attending special and mainstream school environments reported bullying and other stigmatised treatment due to their ID. Most young people in their study with moderate ID were aware of the negative terms used to describe people with ID, such as "thick", and expressed a dislike for these. There is a gap in the literature about the stigma experiences of young people with ID attending post-secondary education settings, such as colleges. Receiving stigmatised treatment at college, or being viewed negatively by peers, may impact on an individual's academic performance or career aspirations, and may also reduce an individual's sense of belongingness at college or to

the college community (Akin and Huang, 2019), which could impact on their selfconcept and opportunities going forward into adulthood.

Experiencing stigmatization can have negative consequences on a young person's sense of self and mental health (Logeswaran et al, 2018; Ali, King, Strydom, & Hassiotis, 2015). The concept of self and how individuals appraise themselves is complex and shaped by both a cognitive and social context. Cognitively, research has demonstrated a developmental sequence in which children's understanding of themselves, others and their social worlds change with cognitive development and social experience (Cunningham and Glenn, 2004) and interactions with significant others (Harter, 1999). Adults and peers are an important influence on young people's developing self-concept. This includes helping to shape their beliefs and attitudes that make up their objective sense of self, as well as how they act in the world (Deakin et al, 2017; Damon and Hart, 1991). Cunningham and Glenn (2004) found that the cognitive ability to categorise is important in developing awareness of one's disability and their study suggests that level of awareness of disability is linked to level of developmental delay. Additionally, informed by Social Comparison Theories, research has shown that those with milder ID's are at an increase risk of internalising stigmatising views due to their cognitive ability to make social comparisons to inform social status (Dagnan and Sandhu 1999; Dagnan and Waring 2004). Brown and Marsh (2018) also highlighted the association between shaming (through stigmatising experiences) and the increased risk of developing mental health difficulties for adults with ID. Furthermore, a positive correlation between self-reported stigma and psychological distress, and the number of contacts with community ID services has been shown (Ali et al 2015).

Cognitive Behavioural Theory (Beck, 1967) provides a framework to understand how stigmatising experiences can impact on an individual view of themselves, others the development of mental health difficulties such as depression through the development of depressive core beliefs (Jahoda et al, 2006). Reiss and Benson (1984) described that adults with ID attending an outpatient service reported an acute awareness of the negative social stigma and social treatment they receive due to having the ID label, and that this awareness had affected their thoughts, feelings and coping styles. It is also thought that, making downward social comparisons with non-disabled peers is thought

to be psychologically threatening (Szivos-Bach, 1993) to an individual with ID's self-esteem. However, Findlay and Lyons (2000) argued that downward social comparison can be used as a protective factor for self-concept by individuals with ID, with an emphasis on their positive identities, rather than on their difficulties. Although there is some understanding about self-concept and mental health among young people with ID, relatively little is known about perception of others with ID.

Deakin et al's (2017) study employed a novel approach to explore self-concept and perception of others with ID among a population of young people with Down syndrome (DS), using an attribution task. In their study, young people with DS were presented with colour pictorial illustrations of simple descriptive words or phrases, and their polar opposites (for example, Friendly/Not friendly). These illustrations and their descriptor pairs were placed in front of two boxes, in which participants "posted" their responses. After viewing the illustrations, and ensuring the participants understood what they were depicting, participants were presented with three pictures; one showing the face of another young person with DS, another of a typically-developing child, and a selfportrait. Participants were then asked to decide whether the picture they were viewing corresponded to one of the descriptor pairs (e.g. needs help/does not need help, good/naughty) by posting the pictures through the corresponding post box. Their results showed that both the DS and typically developing control group were more likely to associate more positive traits with the typically developing photograph. Additionally, the participants attributed significantly more positive traits to the pictures of themselves compared to the photograph of another child with DS. One possible explanation for this difference in ratings is an awareness and internalisation of the negative view's society holds about DS. These may conflict with the individual's actual experiences, for example of supportive relationships with significant others (Deakin et al, 2017), thereby producing conflicting responses. Deakin's study showed that even younger children with Down Syndrome showed an awareness of the stigma associated with Down syndrome.

There is a lack of understanding about how an awareness of stigma and perceptions of self and others with an ID change over time and more specifically as young people make the transition from school to college.

Practically, this study could have implications to the way we understand the experiences of young people with ID, and their developing internal working models. This understanding may allow local health and education providers to examine the support currently available to young people in their care and to inform future provisions of care, perhaps targeting psychological well-being and mental health within this population. With National government drivers such as the Mental Health Strategy Scotland (Scottish Government, 2017 – 2027) and Getting It Right For Every Child (Scottish Government, 2006), aiming to improve the prevalence and incidence of poor mental health among all children and young people, these findings could help inform the understanding of factors contributing to conditions such as anxiety and depression in this population and help inform interventions.

Aims

This study will explore the experience of stigma reported by young people with ID attending college and the nature of their self-perceptions and perceptions of others with ID. The aim is to investigate whether stigma experiences are associated with the young people's perceptions of self and others.

Research Question and Hypotheses

- A. What are the nature and frequency of stigma experiences amongst young people with ID attending college?

Hypothesis

In line with social constructionist theories on development of self-concept (Deakin, 2017; Gergen, 2009), it is hypothesised that:

- A. Young people with ID will perceive themselves more negatively when compared to other young people without ID.
- B. Young people with ID will perceive themselves more positively when compared to other young people with ID.

- C. There will be a positive relationship between the frequency of reported stigma experiences and negative self-perception scores.
- D. There will be a positive relationship between the frequency of reported stigma experiences and negative perceptions of others with an ID.
- E. There will be a positive relationship between the number of reported stigma experiences and psychological wellbeing scores.

Plan of investigation

Design

This study will use a quasi-experimental design with young people recruited from colleges in the west of Scotland. To understand the experiences of stigma among this population, a within group design will be used to explore the attitudes towards disability, attitudes towards self, and experiences of stigma amongst young people with a learning disability.

Materials

A pilot study will be conducted with 3 young people with ID. The pilot study will help establish whether the attribution task is appropriate for use with college students and to establish if any alterations need to be made to the order in which the measures are presented. The following tasks will be administered in the order outlined below.

Measures

Socio-demographic questionnaire

A background questionnaire will be administered to gather information on age, gender, current living arrangements and postcode in order to determine the deprivation index.

Experiences of stigma

The Experience of stigma scale is a 13-point self-report scaled developed by Cooney et al (2006), and rated to confirm reliability. Eight of the items explore the extent to which young people with ID's have experienced stigmatised treatment from key figures in their lives (peers, teachers, parents) through being treated differently (reliability $\alpha =$

0.63) or through being made fun of (reliability $\alpha = 0.48$). The scale also includes five items concerning the frequency of nonthreatening experiences (reliability $\alpha = 0.61$). Participants will be asked to rate the frequency of these experiences for them using on a visual likert scale, and will be asked to generate examples to justify their decisions. These experiences will be documented, and independently rated to determine whether they can be categorised as a stigma experience. A pilot study will be used to confirm reliability of the scale with a college-age population, and the inter-rater reliability will also be calculated.

Self-perceptions beliefs about people with intellectual disabilities and people without disabilities

Participant's beliefs about themselves and other young people with ID will be explored using the novel Attribution Task developed by Deakin et al's (2017) study. Two post boxes will be placed in front of the participant to allow them to post their responses and make the task more engaging. The participant will be presented with colour pictorial illustrations of simple descriptive words or phrases, and their polar opposites: Friendly/ Not friendly, Good / Naughty, Happy/ Sad, Clever/ Stupid, Can do lots of things alone/ Needs help to do things, Does not get called names/ Gets called names, Has lots of friends/ Does not have many friends. These descriptor words will then be placed in front of the post boxes. Participants will then be shown three images; one of a young person with an ID, one of a typically developing young person, and one self-portrait, and a vignette will be developed to explain who each person is. They will be asked to decide which of the descriptor pairs they associated with each of the images, and will post their responses through the corresponding post box.

The Clinical Outcomes in Routine Evaluation – Learning Disability (CORE-LD)

The 30-item version of the CORE-LD will be used to provide a measure of psychological wellbeing. The CORE-LD is widely used in ID mental health services across the UK as a routine outcome measure, and has good psychometric properties (Marshall et al. 2013).

Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II)

Two subtests of the WASI-II (Weschler, 2011) will be used to provide a measure of intellectual functioning in order to give an overall estimate of cognitive ability and to ensure all participants have an IQ below 70. The two-subtest version of the WASI-II includes “Vocabulary” and “Matrix Reasoning”.

Procedure

Pilot / Main Study

The researcher will explain the participation information sheet to the participant and will ensure they wish to participate in the study. Participants will then be asked to sign a consent form and will be informed they are free to withdraw at any time. Participants will then be asked to complete a series of measures in the following order: sociodemographics questionnaire, experience of stigma, self-perceptions and beliefs about people with intellectual disabilities and people without disabilities, the CORE-LD, and the WASI-II. Participants will be given the opportunity for breaks throughout, and testing will be split over multiple sessions if the participants express or show signs of fatigue or loss of attention (as judged by the researcher). Once testing has completed, the participant will be thanked for their participation and given an information sheet letting them know what to do should they have any questions about the study after participating.

Ethical Considerations

Ethical approval will be sought from the University of Glasgow’s research ethics committee. Permission will also be sought from colleges in the West of Scotland to recruit young people aged 16 – 25 years. The researcher will ask permission from the colleges to visit classes specifically aimed at young people with learning disabilities where they will explain the research to the class and ask for volunteers to participate in the study. Prior to participating, the researcher will discuss the participation sheet with the participants and ensure they do wish to participate. They will also be asked to sign a consent form if they wish to participate, and they will be informed that they are free to drop out at any point. The researcher will also identify and contact each of the participants key worker or pastoral support (where applicable) to inform them of the

study and ask if participants would be signposted to them for support should they become upset.

Although it is not expected that participants will find participating in this study distressing, it is acknowledged that discussing experiences of stigma may be upsetting for some participants. The materials used in this study have been used in previous literature, and no adverse reactions have so far been reported. However, should a participant become distressed during the study, data collection with them will immediately stop and participant will be asked if they would like to resume again after a short break, or to stop altogether. Participants will also be signposted to their key worker or pastoral team for further support.

All information collected will be stored securely in line with the University's GDPR policy on data protection and security, and will only be accessible to those directly involved with the study. All information will be confidential, and identifiable information will be anonymised.

Recruitment

Following ethical approval from The University of Glasgow research ethics committee, Colleges in the West of Scotland will also be contacted and permission will be sought to recruit students. A power calculation will be attempted based on Deakin et al's (2018) study in order to identify a sample size

Inclusion criteria:

- Young people attending colleges in the west of Scotland aged between 16 – 25 years.
- Must be enrolled in a college course for people with ID, whose ID status will be confirmed by the WASI-II two subtest form.

Statistical analysis

Quantitative data will be collected and analysed using SPSS statistical package and content analysis of participant responses will allow for the collection of information on the types of stigma experienced.

Within group analysis

Participants characteristics and socio-demographics will be outlined in order to evaluate the influence of level of ability and socio-economic status on the dependent variables.

Descriptive data of participants scores across the range of measures will also be reported for; stigma experience, self-concept and believes about others and themselves.

Beliefs about self and others with ID

The study will examine whether there is a difference between the attributions towards:

1. Others with ID and those without ID
2. Self and others with ID
3. Self and others without ID

Correlational Analyses

The study aims to use correlational analysis to examine the relationship between:

1. Stigma experience scores and psychological wellbeing scores
2. Stigma experience scores and the number of positive descriptors applied to themselves.
3. Stigma experience scores and the number of positive descriptors applied to others with a disability.

However, the type of correlations carried out will depend on whether the data meets the assumptions for parametric or non-parametric analyses

Setting and equipment

During the data collection phase, access to the test-materials and self-report measures will be required. A quiet room within the college will be used for data collection, on a 1:1 basis. Exact timings will be established during piloting, with the possibility of having two data collection sessions per participant.

Health and Safety Issues

Participants

Data collection will take place during college hours. The researchers will make the college's student services department aware of the study, and will monitor the participants throughout the study and will sign post the participant to their services if further support is required.

Researcher

The researcher will familiarise themselves with local safety procedure, what to do in the event of fire and who to contact should concerns arise.

Financial Issues

The WASI-II kit will be borrowed from the training course, however response forms for this may need to be ordered. Depending on the location of the colleges, researcher travel expenses may need to be reimbursed and costs of participant information sheets and consent forms will also be considered.

Timetable

June 2020: Final approved MRP proposal

June – September 2020: Apply for and gain ethical approval

October 2020 – February 2021: Recruitment and data collection

(December 2020 – review of recruitment)

March 2021: Analysis

April - June 2021: Write-up

July 2021: Final submission of MRP

September 2021: Viva

References

Abed, M. G. (2017). Inculcating Positive Thinking in the Self-Concept of Children with Learning Difficulties. *Journal on Educational Psychology*, 10(3), 1-10.

Akin, D., & Huang, L. M. (2019). Perceptions of College Students with Disabilities. *Journal of Postsecondary Education and Disability*, 32(1), 21-33.

- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in developmental disabilities, 33*(6), 2122-2140.
- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England. *Journal of Affective Disorders, 187*, 224-231.
- Ali, A., Strydom, A., Hassiotis, A., Williams, R., & King, M. (2008). A measure of perceived stigma in people with intellectual disability. *The British Journal of Psychiatry, 193*(5), 410-415.
- Beck, A. (1967). *Depression: Clinical, experimental, and theoretical aspects*. New York: Hoeber.
- Brown, M., & Marsh, L. (2018). Adults with intellectual disabilities experience shame that leads to psychological distress and mental illness that requires assessment and treatment. *Evidence-based nursing, 21*(3), 86-86.
- Chalk, H. M. (2016). Disability self-categorization in emerging adults: Relationship with self-esteem, perceived esteem, mindfulness, and markers of adulthood. *Emerging Adulthood, 4*(3), 200-206.
- Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research, 50*(6), 432-444.
- Cunningham, C., & Glenn*, S. (2004). Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability. *International Journal of Disability, Development and Education, 51*(4), 335-361.
- Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research, 43*(5), 372-379.
- Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice, 11*(4), 247-254.
- Damon, W., & Hart, D. (1991). *Self-understanding in childhood and adolescence* (No. 7). CUP Archive.
- Deakin, K., Moore, D. G., & Jahoda, A. (2017). Children and young people with Down syndrome: Their awareness of Down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities, 31*(6), 1197-1208.

- Festinger L. (1954) A theory of social comparison processes. *Human Relations* 7, 117-140
- Finlay, W. M., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39(1), 129-146.
- Gergen, K. J. (2009). *An invitation to social construction* (2nd ed.). Sage Publications Ltd
- Getting it Right for Every Child (GIRFEC), Scottish Government.
- Harter, S. (1999). *The construction of the self: A developmental perspective*. New York: Guilford Press
- Heiman, T., & Olenik Shemesh, D. (2019). Predictors of cyber-victimization of higher education students with and without learning disabilities. *Journal of Youth Studies*, 22(2), 205-222.
- Jahoda, A., Dagnan, D., Jarvie, P., & Kerr, W. (2006). Depression, social context and cognitive behavioural therapy for people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 81-89.
- Jahoda, A. and Wilson, Alastair and Stalker, K. and Cairney, A. (2010) Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*
- Joseph A. Guarneri, David E. Oberleitner & Sara Connolly (2019) Perceived Stigma and Self-Stigma in College Students: A Literature Review and Implications for Practice and Research, *Basic and Applied Social Psychology*, 41:1, 48-62
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 27(1), 363-385.
- Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 533-542.
- Maïano, C., Coutu, S., Morin, A. J., Tracey, D., Lepage, G., & Moullec, G. (2019). Self-concept research with school-aged youth with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 238-255.
- Martlew, M., & Hodson, J. (1991). Children with mild learning difficulties in an integrated and in a special school: comparisons of behaviour, teasing and teachers' attitudes. *British Journal of Educational Psychology*, 61(3), 355-372.
- Marshall K., Coffait F.-M. & Willoughby-Booth S. (2013) Assessing distress among people with intellectual disabilities. *Learning Disability Practice* 16, 26-30

- May, A. L., & Stone, C. A. (2010). Stereotypes of individuals with learning disabilities: Views of college students with and without learning disabilities. *Journal of learning disabilities*, 43(6), 483-499.
- Norwich, B., & Kelly, N. (2004). Pupils' views on inclusion: moderate learning difficulties and bullying in mainstream and special schools. *British educational research journal*, 30(1), 43-65.
- O'Byrne, C., & Muldoon, O. (2017). Stigma, self-perception and social comparisons in young people with an intellectual disability. *Irish Educational Studies*, 36(3), 307-322.
- Reiss, S., & Benson, B. A. (1984). Awareness of negative social conditions among mentally retarded, emotionally disturbed outpatients. *The American journal of psychiatry*.
- Scanlon, G., McEnteggart, C., & Barnes-Holmes, Y. (2019). The academic and social profiles of pupils with attention deficit hyperactivity disorder and mild general learning disability in mainstream education in the Republic of Ireland. *Journal of Research in Special Educational Needs*, 19(4), 344-352
- Schalock RL, Borthwick-Duffy SA, Bradley VJ, et al. (2010) Intellectual Disability: Definition, Classification, and Systems of Supports. Washington: *American Association on Intellectual and Developmental Disabilities*.
- Marshall, K., Coiffait, F. M., & Willoughby-Booth, S. (2013). Assessing distress in people with intellectual disabilities. *Learning Disability Practice*, 16(3).
- Mental Health Strategy 2017 – 2027, Scottish Government (2017)
- Sheridan, J., & Scior, K. (2013). Attitudes towards people with intellectual disabilities: A comparison of young people from British South Asian and White British backgrounds. *Research in developmental disabilities*, 34(4), 1240-1247..
- Szivos-Bach, S. E. (1993). Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap. *Mental Handicap Research*, 6(3), 217-236.
- Pestana, C. (2015). Exploring the self-concept of adults with mild learning disabilities. *British Journal of Learning Disabilities*, 43(1), 16-23.
- Vignes, C., Godeau, E., Sentenac, M., Coley, N., Navarro, F. Grandjean, H. 2009. Determinants of students' attitudes towards peers with disabilities. *Developmental Medicine & Child Neurology*, 51: 473–479.
- Weschler, D (2011) Weschler Abbreviated Scale of Intelligence – two subtest. *Pearson Clinical*

Appendix 2.2 – Research Equipment Cost Form

Trainee Maria Johnson

Year of Course 2 Intake Year 2018

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	1 ream white paper Envelopes DL	£2.95 £4.12 Subtotal: £7.07
Postage	Posting invite to participate letters and stamped return envelopes	62p x 40 (initial invite letters) 62p x 40 (stamped return envelopes) Subtotal: £99.20
Photocopying and Laser Printing	Printing of information and consent forms and debrief sheet.	5p x 40 (info sheet) 5p x 40 (consent forms) 5p x 40 (debrief sheet) Subtotal: £6
Equipment and Software	Dictaphone voice recorder to record conversations to be purchased	Subtotal: £40
Measures	N/A	
Miscellaneous	N/A	
Total		£152.27

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 2.3 – Research Health and Safety Form

Trainee: 0906993j

Year of Course: 2nd Year

Year of Intake: 2018

1. Title of Project	The experiences of young people with an intellectual disability and the impact of these on sense of belonging and perception of self and others with disabilities.
2. Trainee	Maria Johnson
3. University Supervisor	Prof. Andrew Jahoda
4. Other Supervisor(s)	N/A
5. Local Lead Clinician	TBC
6. Participants (age, group or sub-group, pre- or post-treatment, etc)	Young people with intellectual disabilities attending colleges in the West of Scotland, aged between 16 – 25 years.
7. Procedures to be applied (eg. questionnaire, interview, etc)	1 x demographics questionnaire 1 x semi-structured interview
8. Setting (where will procedures be carried out?) i) Details of all settings	Data collection will be carried out virtually, through the use of Microsoft Teams or similar technology. Participants will require the use of a quiet room within the college building, within their own home, or within a third sector organisation specifically for people with learning disabilities. Data collection will be on a 1:1 basis, and should take between 30-60 minutes.
ii) Are home visits involved	No

<p>9. Potential Risk Factors Considered (for researcher and participant safety):</p> <ul style="list-style-type: none"> i) Participants ii) Procedures iii) Settings 	<ul style="list-style-type: none"> i) This participant sample is not normally associated with dangerous or unpredictable behaviour. ii) The procedures in the study are same/similar to those used by clinical psychologists with these populations and are not normally associated with production of significant distress. However, it is acknowledged that talking about stigma experiences may be upsetting for the participant and the researcher will continuously monitor for signs of distress and will follow procedures outlined in the proposal. No risks are expected from this task. iii) If carried out in college or third sector settings, those local procedures already in place will be followed to minimise risk to staff and these are thought to be adequate in the context of the proposed study. If carried out in the participants home, the researcher will ensure there is a family member/carer in the same house who can support the participant if needed.
<p>10. . 10. Actions to minimise risk (refer to 9)</p> <ul style="list-style-type: none"> i) Participants ii) Procedures iii) Settings 	<ul style="list-style-type: none"> i) The researchers will make the college's student services department or a nominated member from the third sector organisation or a family member/carer aware of the study, and will monitor the participants throughout the study and will sign post the participant to their services if further support is required. ii) Although it is not expected that participants will find participating in this study distressing, it is acknowledged that discussing experiences of stigma may be upsetting for some participants. However, should a participant become distressed during the study, data collection with them will immediately be paused. iii) Local health and safety policies in place at each college and organisation will be followed, including fire protocols and when to direct participants for support should they become upset during the course of the study.

Appendix 2.4 - Ethical Approval Letter

Dear Professor Andrew Jahoda

MVLS College Ethics Committee

Project Title *The experiences of young people with an intellectual disability and the impact of these on sense of belonging, and perception of self and others with disabilities.*

Project No 200200003

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 original application.
- 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)
- The participant identifiable data (contact details) should only be held for as long as is needed for this study.
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any in-person research activity should adhere to local infection control guidance and will require authorisation from relevant departmental leads.
- 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 within 3 months of completion.

Yours sincerely

Terry Quinn

FESO, MD, FRCP, BSc (hons), MBChB (hons)

Senior Lecturer / Honorary Consultant

Appendix 2.5 – Participant Information Sheet



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

PARTICIPANT INFORMATION SHEET

A research study looking into the experiences of young people with learning disabilities who have left school.



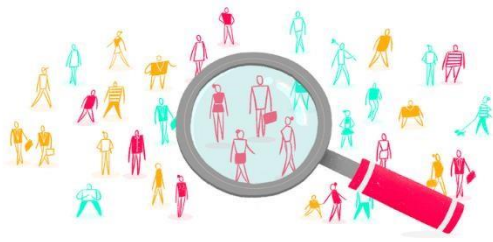
Please read this information sheet.



You can ask someone to read it with you.



My name is Maria
I am studying at The University of Glasgow



What is this study about?

I am doing a research study about the experiences of young people with learning disabilities.



I want to know more about how life has been for young people since leaving school and how they think about themselves.

I hope this will help colleges and services learn how to support young people to have positive experiences.

Why am I being asked to take part?



I am asking you if you would like to take part because you are a young adult aged between 16 – 26 years old who attends college in the West of Scotland.

I would like to meet with 10 young people to talk about their experiences since leaving school.

YES

NO



Do I have to take part?

No, you do not have to take part. Taking part is voluntary and it is okay if you do not want to.

If you do want to take part you will still be free to withdraw at any time.



What will happen?

We will have a conversation over Microsoft Teams videocall, or by telephone.



We will meet for 1 hour



I will ask you to read a consent form and tell me you are happy to take part in the study.



I will ask you some questions to find out more about you and your experiences

I will use a voice recorded to record our conversations.



Will anything bad happen to me if I take part?

It is unlikely that anything bad will happen if you take part.

Some people might feel upset when talking about their experiences.



But you can stop at any time and you don't have to talk about anything that might make you upset.



Are there any good things about taking part?

Some people like sharing their opinions with other people and find this interesting.

Will other people know what I have said?



Everything that you say will be private.

The only time I will have to tell other people about what we spoke about is if I am very

worried about you or someone else. But I would let you know if I needed to do this.



All of your information will be stored safely on a computer or in a locked filing cabinet.



I will follow the government and University's laws to make sure your information is kept safe.

What will happen with the information?



I will write a report about what you and other people have said. Your name will not be used in the report.

Other people will be able to read the report. A copy of the report will be kept in the University of Glasgow Library.

I can give you a copy of the results if you would like.

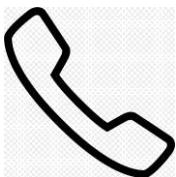
Data Privacy Notice

All study data will be held in accordance with The General Data Protection Regulation (2018). Project data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures

How can I take part?



If you would like to take part you can:
Fill in the reply slip and post it to me.



You can call or email me to say
you would like to take part



Or you can ask family or staff to contact
me to let me know.



I will contact you using the telephone number or email you give me and we can arrange a time for a Microsoft Teams video-call or telephone call.

If you want to speak to me about the study you can contact me:

Maria Johnson

Or you can get in touch with my supervisor with any questions:

Prof. Andrew Jahoda

Trainee Clinical Psychologist
Institute of Mental Health and Wellbeing,
University of Glasgow,
Gartnavel Royal Hospital,
Glasgow,

Consultant Clinical Psychologist
Institute of Mental Health and
Wellbeing, University of Glasgow,
Gartnavel Royal Hospital,
Glasgow,

G12 0XH

G12 0XH

Telephone: 0141 211 0607

Telephone: 0141 211 0607

Email:

Email:

Andrew.jahoda@glasgow.ac.uk

Thank you for taking time to read this information and think about this study.



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

Privacy Notice

Your Personal Data

The University of Glasgow will be what's known as the 'Data Controller' of your personal data processed in relation to this research study. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it

We are collecting your basic personal data such as name, email address and limited special categories of data such as ethnicity, as part of data for this research study. We will only collect data that we need in order to provide and oversee this service to you.

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is consent, meaning that you have said it is okay for us to collect this information as part of the research study.

What we do with it and who we share it with?

All the personal data you submit is processed by staff at the University of Glasgow in the United Kingdom and will be stored securely.

How long do we keep it for?

Your data will be retained by the University for 10 years after the research study has ended. After this time, data will be securely deleted.

What are your rights? *

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability. You also have the right to withdraw your consent at any time.

If you wish to exercise any of these rights, please submit your request by contacting dp@gla.ac.uk.

*Please note that the ability to exercise these rights will vary and depend on the legal basis on which the processing is being carried out.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter. Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) <https://ico.org.uk/>

As we are collecting data remotely, the researcher will ask you to verbally provide consent to the university processing your personal data for the purposes outlined above, before you begin the study.

Appendix 2.6 - Consent Form











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









Consent form

Working Study Title: A research study looking into the experiences of young people with learning disabilities who have left school.

Researchers: Maria Johnson (Trainee Clinical Psychologist) and Prof Andrew Jahoda (supervisor).

Please tick the boxes which apply

<p>I have read and understood the information about taking part in the study.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I have had the chance to ask questions about taking part in the study.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I understand that I do not have to take part in the study and I can withdraw at any time without giving a reason.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I understand that the interview will be recorded by the interviewer, Maria Johnson, and only be used for the purposes of this study.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>

<p>I understand that the researcher, Maria Johnson, may publish direct quotes of what I have said. But this will not include my name, information about who I am, and others won't be able to identify me from this.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I understand that the researcher, Maria Johnson, may be required to tell someone about what we discussed if I mention something during the interview that makes the researcher concerned about my safety or that of others.</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I understand how my information will be stored and I'm happy for the University to process my personal data for the purposes of this research study. Data Privacy Policy - all of my data will be held in accordance with The General Data Protection Regulation (2018). Project data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures)</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>
<p>I agree to take part in this study</p>	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Yes <input type="checkbox"/> </div> <div style="text-align: center;">  No <input type="checkbox"/> </div> </div>

Name of participant

Date

Signature

Name of Researcher

Date

Signature

Semi-Structured Interview Schedule

Introduction

Thank you for agreeing to take part in our research. My name is Maria and I am a Trainee Clinical Psychologist from the University of Glasgow. The aim of the interview is to hear about your experiences, particularly of school and college. I will ask you some questions, but you don't have to answer these questions if you don't want to. The interview will take about one hour. If you would like a break, or would like to stop at any time, please let me know.

Everything we discuss will remain confidential. However, if you say anything that makes me believe you or someone else is at risk of harm, or is being harmed, I will be required to tell someone else about it just to keep you and others safe.

Our interview will be recorded to capture exactly what you have said. Afterwards, I will type it up and remove any details which could identify you or anyone you speak about.

I will start by asking a question and will ask follow-up questions for further information. When I ask to follow up questions, this does not mean that your answer wasn't 'right' or 'good enough', it's just my way of ensuring that I have got as much information as possible to help understand your experience better.

- Do you have any questions?

Start Recording

- Discuss and complete consent form

1. I'm interested in knowing a bit about you, can you start off by telling me a bit about your family.

[Prompt: who do you live with? Any siblings?]

2. You mentioned your sibling, would you say you are quite similar (lots of things in common) or different to your sibling?

[Prompt: how described themselves? Ever been described differently, in a way you didn't like?]

3. Did you go to the same school as your sibling?

[Prompt: What other people say about your school? how did you feel about this?]

4. I'm interested to know what school was like for you?

[Prompt: part of any clubs? anything you found difficult? What type of support did you get at school? How did you feel about this?]

5. What do you think your sibling/friends thought of school?

[Prompt: do you think they found anything difficult? What type of support did they get at school?]

6. Did you ever feel "left out" at school?

[Prompt: what did you think of yourself at school? Did experiences change this? How did it feel?]

7. What courses are you doing at college?

[Prompt: what do you think of these courses? What do you think other people think of these courses?]

8. I'm interested in hearing how you're finding college?

[Prompt: anything good/difficult about it?]

9. I'm wondering if you could tell me about some of the differences you've found between school and college?

[Prompt: independence, inclusion]

10. Do you think you get treated any differently now you're a college student?

[Prompt: adult, have you changed in any way since starting college? How feel]

11. I'm interested to know if you feel like you "fit in" at college?

[Prompt: any clubs/Anything you'd like to do/be involved in but feel you can't?]

12. Could you tell me about your friends at college?

[Prompt: what was it like making new friends? Did you have any worries about making new friends/meeting new people? Do they do the same course? How feel about telling your friends what school you went to?]

13. I'm interested to know what you do at break/lunch times? Pre-covid
14. What would you like to do after college?
15. Thank you for speaking with me. That is all my questions asked – is there anything you'd like to add that I've not asked about?
16. Sometimes I might go away and realise I've forgotten to ask something. If this happens, would you mind if I get back in touch?

Stop Recording

Follow Up

- Collect demographic information

Age:

Gender:

Postcode:

- Verbally debrief the participant and ensure the participant is not distressed about anything discussed within the interview and ensure appropriate advice and sign posting is offered
- Ask the participant if they would like to be notified of any dissemination of the findings from the research
- Ask if there are any further questions in relation to the interview and/or research
- Thank for time and involvement in the project.

Appendix 2.8 – Extract of Coding

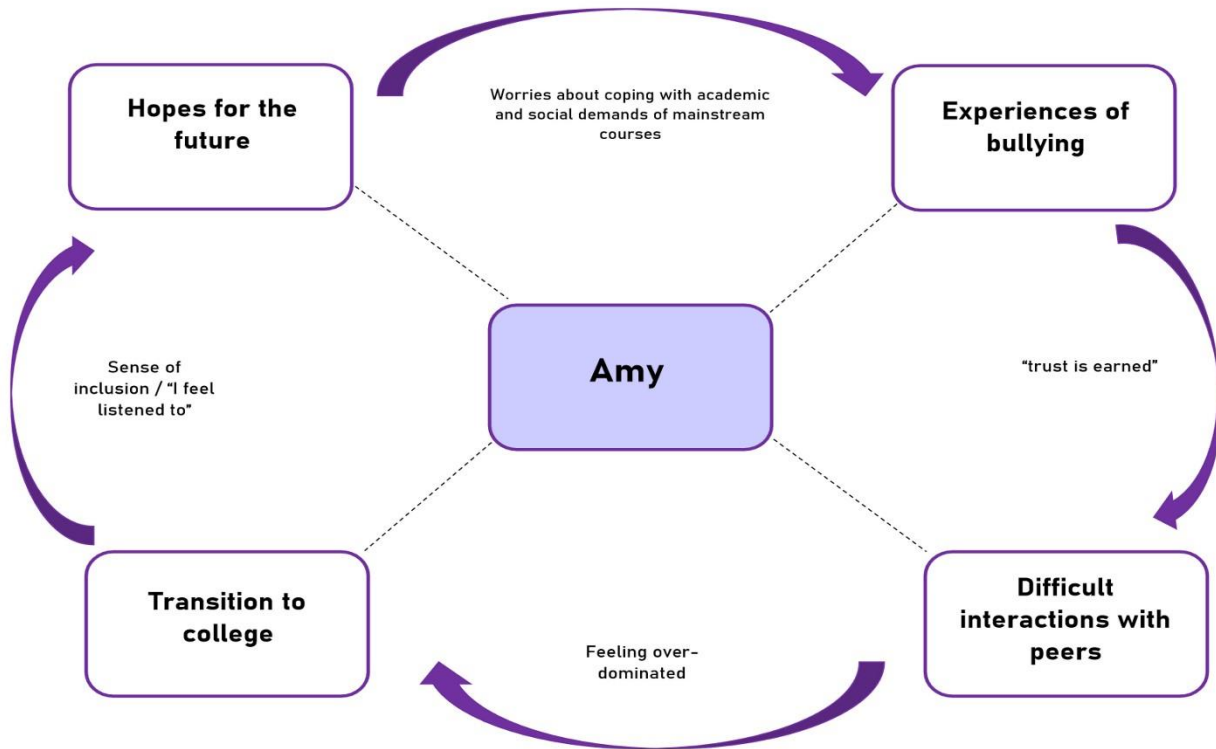
<p>Feeling down</p> <p>Positive social relationships with peers Feeling less important Peer Support</p> <p>Witnessing bullying of others</p> <p>Sympathy for others</p> <p>Feeling important Positive view of self Talented</p>	<p>"It just makes me feel down [pause] it makes me feel like they're purposely trying to do this so I feel less important to them. You see that in typical bullies, you get them... [silence]"</p> <p>"eh, sometimes, but like some of my best pals keep telling me I need to keep my head up, and that. And I trust them because I know they're more important to me than [the] people who try to comment and make them[selves] feel more superior than me..."</p> <p>"Aye, I've seen my pals going through it worse than others"</p> <p>"Yeah, and I can feel sympathy for them. I can feel sorry for somebody and I would just go over and try to console them [pause]"</p> <p>[Talking about reading the Chimp Paradox" book] "Like I'm learning it and getting used to the brain because I realised the chimp bit of the brain is where the instinct comes from but the human but is logic based, they think rationally so they search for the</p>	<p><u>Having an LD is humiliating? Perhaps knowing himself that he has an LD and could be associated with this group, but choosing to avoid this? Avoiding his LD label/status/his difficulties?</u></p> <p>Impact of stigma experiences in community Negatively impacts on mood <i>Pause and tailing off – gives sense that this was difficult for him to recall/discuss</i></p> <p><u>Feeling less important vs feeling more important – others / associating with LD group can make him feel less important. What are the consequences of feeling less important? Less important than whom? Feeling the need to overcompensate by using complex language etc.?</u></p> <p>Experience of stigma and utilising peer support as way of coping.</p> <p>Experience of stigma – witnessing friends being bullied <i>"them" – creating distance?</i></p> <p>Feels sympathy for others who experience bullying. <i>Pause felt like it was emotionally difficult for him to recall these experiences.</i> <u>Again, appears evidence of trying to demonstrate his importance – feeling important and empowered seems to be</u></p>
<p>Experience of stigma in community Awareness of stigma in community Emotional conflict Sense of belonging Choosing a different path Distance from LD associations</p>	<p>"Eh, I don't really know. I don't think they know the terms of that school. But a couple of my pals from down the street, like when I said some of them had made comments about that school like it being a mongo school for example, it really made me want to get out of that school and go to another one."</p>	<p>Experience of stigma in the community in relation to LD Awareness of stigma in the community. Sense of belonging – conflict. <u>Aware that attending his school was perhaps stigmatising and, when confronted with this, wanted to belong to another group. Conflict between sense of belonging – not feeling like he belongs in a special needs school from a society level. Feeling like he wanted to break away from this association and follow a different path.</u></p>

Appendix 2.9– Extract of Master Coding Document

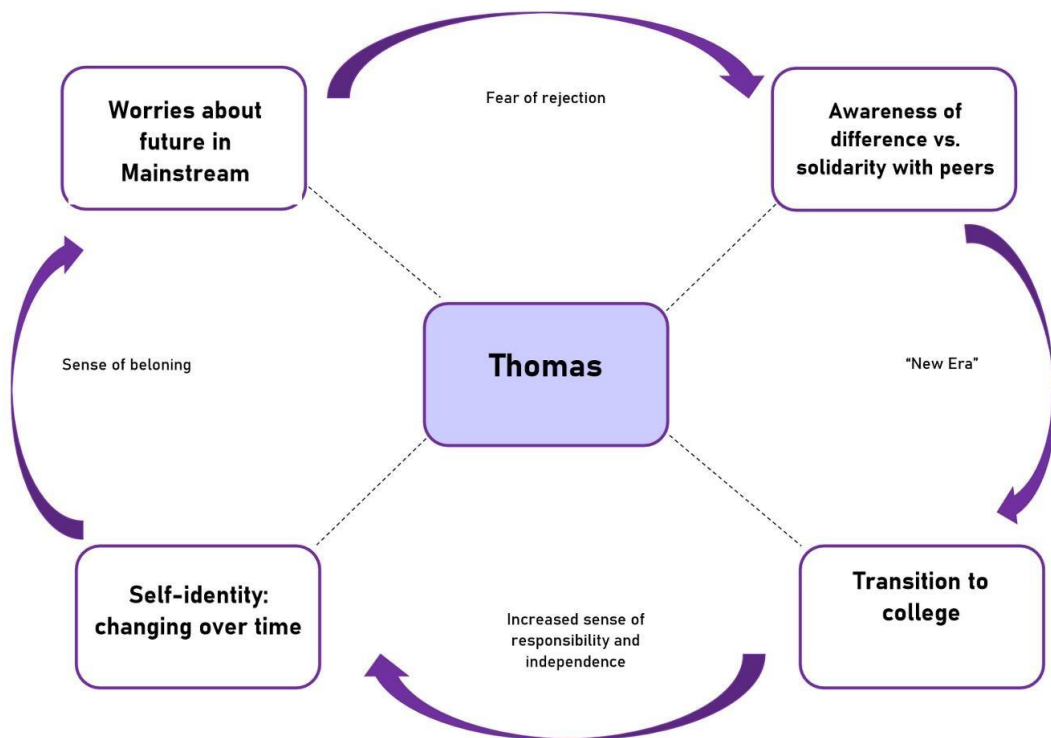
Theme	Participant & Quote	Additional Comments
Experience of Stigma	<p>Thomas (1): “Yeah, there’s been comments like... [pause] like, there was one example of “mongo” and someone asked me if I went to a “mongo school” and I didn’t really want to say yes because I didn’t want to be humiliated in a way so I just, I kinda avoided it, and avoided the answer. I wasn’t trying to be in denial, I just tried to avoid the answer.”</p>	<p>Feeling humiliated <i>Hesitation at sharing this story/using the word – aware it is offensive term.</i> <i>“Humiliated” really strong connotations of shame.</i></p>
	<p>Kevin (2): “erm well, I’ve had people who’ve said it’s rubbish, “I don’t like the people in it” erm, [this was said] by people who used to go to it [school] who hated it completely. But I never hated it that much”</p>	<p><i>“hated” – strong word, perhaps reflecting people had strong opinions about the school? –</i> <i>“People in it” – implies a certain “type” of person goes to the school?</i></p>
	<p>Amy (4): “because one time someone came and tripped me up and scarred my knee really badly and it <u>bleeded</u> (sic) now I’m stuck with a scar for life.”</p>	<p><i>“Stuck” may imply that this has been put upon her and is a burden to bear, something she is not able to get rid of.</i></p>
	<p>John (5): “Because a lot of people can have a lot of friends in secondary but because I wasn’t that sociable, I didn’t have that many. I had some friends in secondary so it was alright.”</p>	<p>Experience of having few friends - <i>“Just got on with it” – suggests he recognised he was unable to change the situation? Perhaps making the best with what he had?</i></p>

Appendix 2.10 – Individual participant schematics

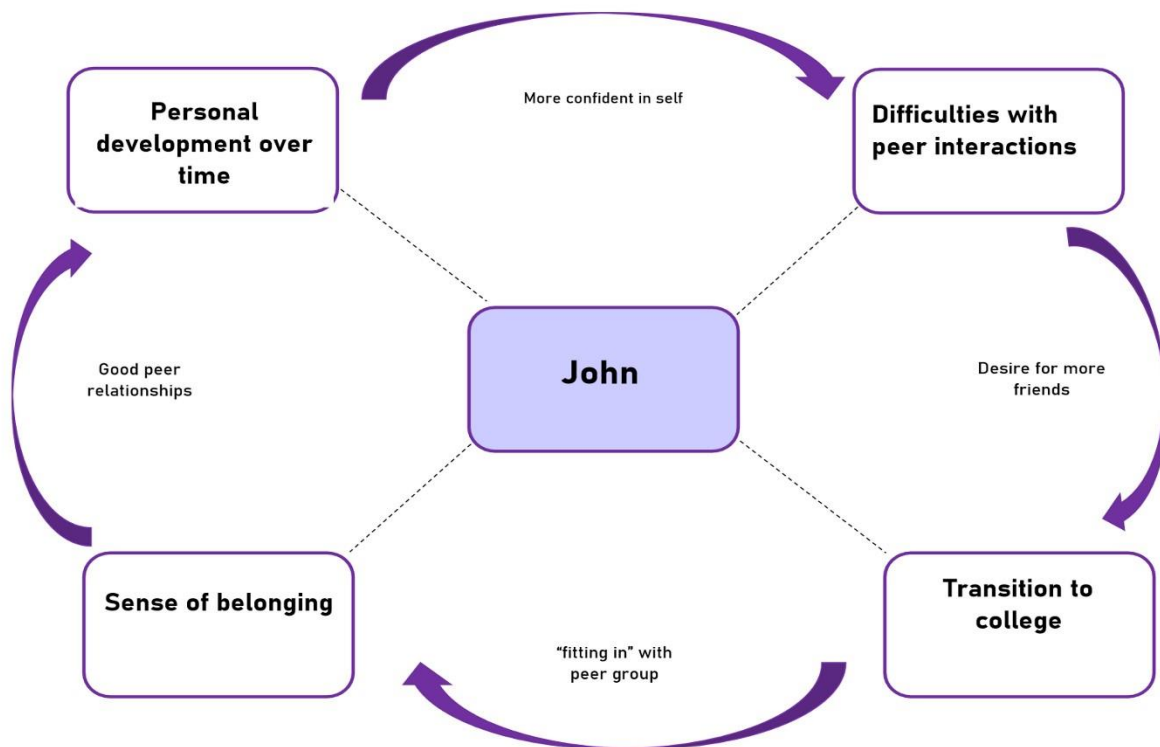
Participant: Amy



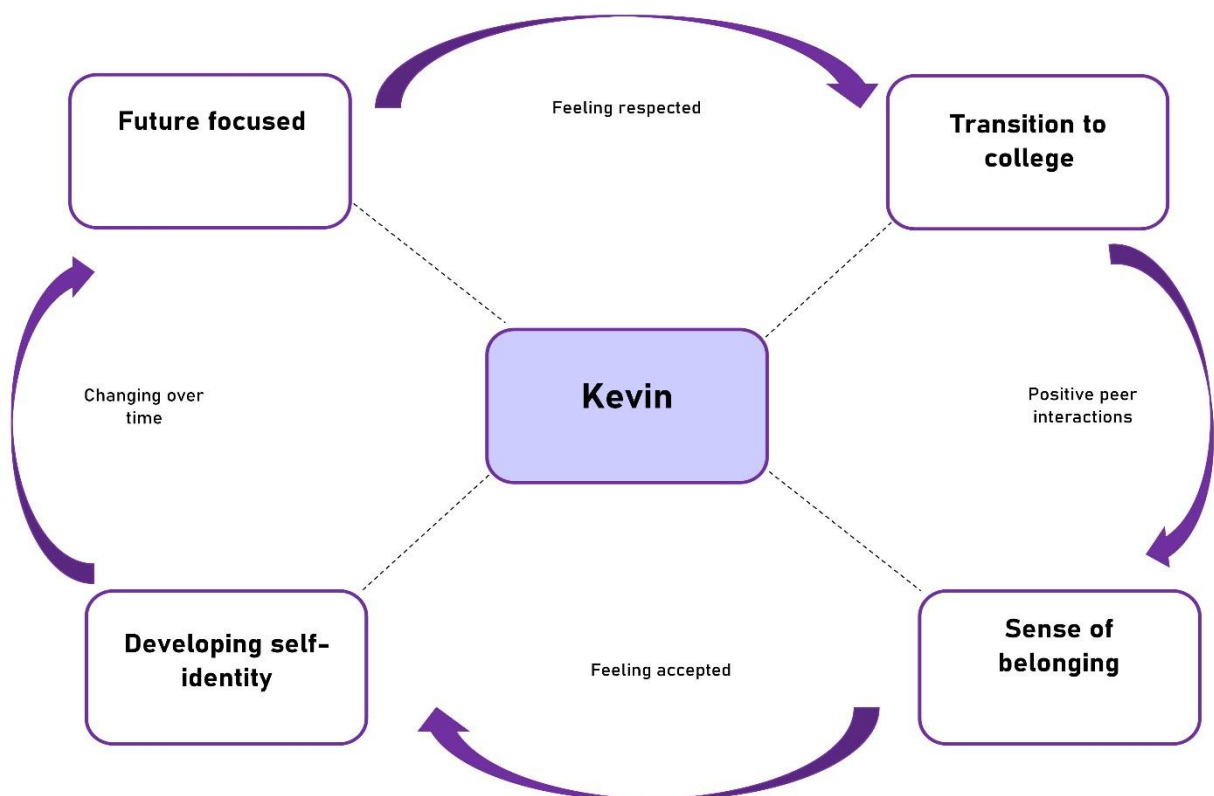
Participant: Thomas



Participant: John

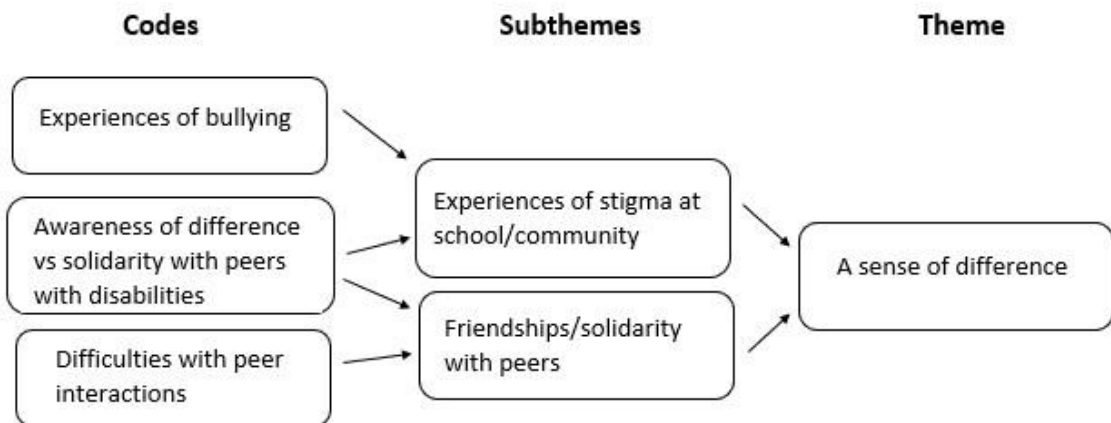


Participant: Kevin

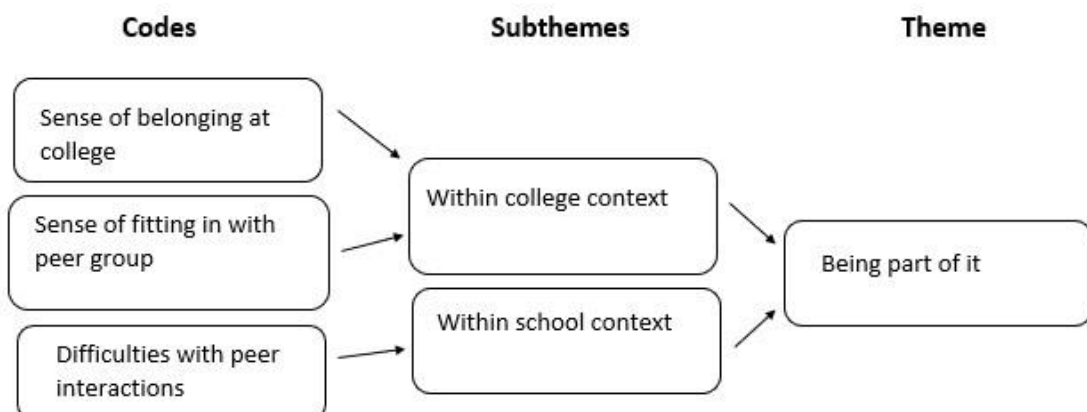


Appendix 2.11 – Final Thematic Maps

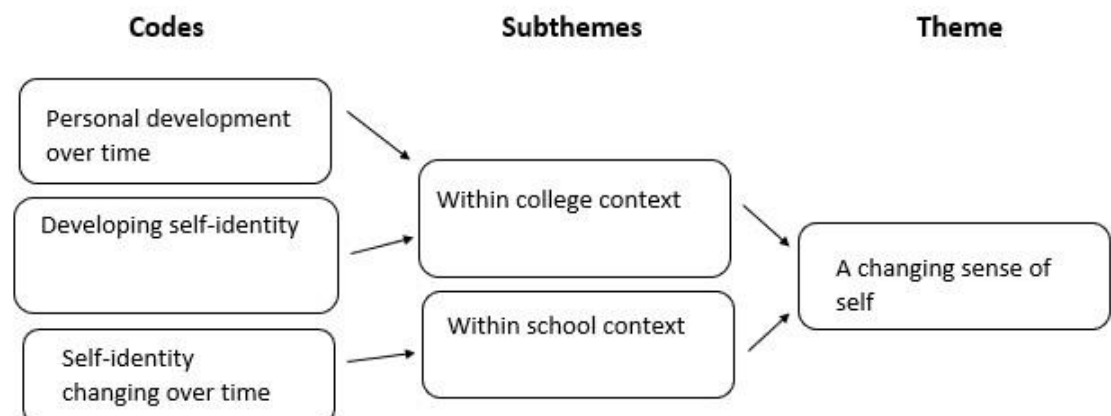
Theme 1: “They don’t fully understand what my school was like”: A sense of difference



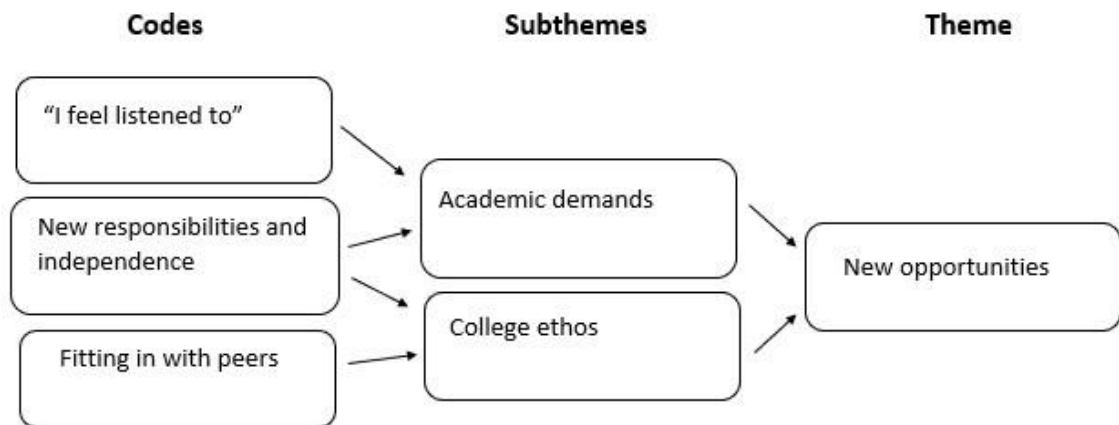
Theme 2: “It was great! I felt like I wasn’t left out anymore”: Being part of it



Theme 3: “When I go to college, it’s a completely different set of confidence”: A changing sense of self



Theme 4: “It’s given me so many benefits”: College and new opportunities



Theme 5: “It’s just a disability... but I rise back”: I can do it

