THE UNIVERSITY OF HULL

Personal Experiences of Living with an Intellectual Disability

being a Thesis submitted in partial fulfilment of the requirements for the degree of

Doctor of Clinical Psychology

in the University of Hull

By

Gemma Whitney
BSc (Hons)

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Acknowledgements

Firstly, I would like to thank the staff at the services who helped me to recruit participants, your enthusiasm for the project was invaluable. To all the individuals who participated in my research, without your willingness to share your stories with me, I would not have a thesis to write.

I would also like to thank all the staff on the course, your support throughout these three years has been incredible, especially at the most challenging times. I would especially like to thank Dr Nick Hutchinson and Dr Lesley Glover, you encouraged me to keep going with this project and helped me stay calm in times of panic. I will not forget Lesley’s advice to ‘keep putting one foot in front of the other’, without that the whole project would have become overwhelming at times.

To all the trainees, we started this together and I will never forget the fun times we have had throughout the course. Now we will all go our separate ways, and I wish everyone all the best in everything that they do.

To my family, Mum, Dad, Sam and Dave thank you for all the support and love that you have given me my whole life and encouragement in everything I’ve done. I wouldn’t have become the person I am today if it wasn’t for all of you.

Finally, to Tom, thank you for sticking by me through times of stress whilst doing this Doctorate. With you by my side everything seemed to become easier. I love you, and I can’t wait for the future we have ahead of us.
Overview

This portfolio thesis contains three separate parts; a systematic literature review, an empirical study and corresponding appendices.

Part one is a systematic literature review, in which the theoretical, conceptual and empirical literature relating to the experiences of individuals with Intellectual Disabilities (ID) in the post-secondary transitional period is reviewed. A systematic database search was carried out which identified 11 papers suitable for review. Thematic synthesis was used to analyse the data and a quality assessment was completed. Four themes were derived from the data which were, ‘Transition’, ‘Influential roles’, ‘Role of students with ID’, and ‘Outcomes’. Implications of the findings and considerations for future review are discussed.

Part two is an empirical paper, which explores the lived experiences of people with ID, utilising theories from Second Wave Positive Psychology and a Dual-System’s Model. Nine adults with ID were interviewed. Interpretive Phenomenological Analysis (IPA) was used to analyse the data. Three superordinate and six subthemes were identified. The superordinate themes were, ‘Identity’, ‘Managing Life’s Difficulties’, and ‘Approaches to Life’. Implications, considerations for future research, strengths and limitations are discussed.

Part three comprises the appendices, which contain the approval letter from the Faculty of Health and Social Care Research Ethics Committee at the University of Hull, documents used in the empirical research, a reflective statement considering the research process and an epistemological statement.

Overall word count (excluding tables, references and appendices): 13,604
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Table 1: Superordinate and subthemes derived from the data.
Part 1: Systematic Literature Review

This paper is written in the format ready for submission to *Disability & Society*. See Appendix A for submission guidelines.

Total word count: 5610 (excluding abstract, tables, references and appendices)
The Post-Secondary Transition Period: How is it Experienced by People with Intellectual Disabilities?

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Abstract

Transitions are an inevitable part of life; there are transitions in careers, home life and relationships. These may be challenging for people with Intellectual Disabilities (ID), they may feel different to their non-disabled peers and difficulties become exacerbated. The current review aims to examine the experiences of people with ID in the post-secondary transition period (leaving secondary school and beginning adult life). A systematic literature review was carried out until March 2017. A quality checklist was adapted from the National Institute for Health and Care Excellence (NICE 2012) and the Strobe Checklist (STROBE Statement 2007) to assess the quality of papers. Thematic synthesis was used to analyse the data. The findings suggest that people with ID find it difficult to make their voice heard, and opportunities are limited. Facilitating the development of self-determination, resilience and self-advocacy enables individuals to take control and achieve their goals in this period.

Key Words: Intellectual Disability, Post-secondary, Transition, Employment, Post-school education
Introduction

Transition Periods

Transitions are an inevitable part of life; people will transition from childhood to adulthood; from school to work; and living with parents to living independently (Hayes-Hammer et al. 2000). Previously there has been a view that transition periods are a linear process (Cooney 2001). Erikson’s (1950) Psychosocial Stages is an example of this. In the ‘Adolescence Stage’ (12-18), identity is created and people aim for inclusion with peers. In the ‘Young Adult Stage’ (18-35), romantic relationships develop and people become settled. More recently, it is thought that transitions occur throughout our lifetimes in a non-linear fashion (Cooney 2001). This view suggests that people do not move through each stage in a consecutive fashion, but considers external factors impacting transition stages such as, the community, attitudes and opportunities which could result in individuals moving between stages.

Transitions in People with ID

Periods of transition can be challenging and complex for individuals with ID (Cooney 2001). As such, a substantial body of research has been undertaken in this area. Using the Erikson Psychosocial Stage Inventory (EPSI, Rosenthal et al. [1981] as quoted by Pickar and Tori [1986]), Pickar and Tori (1986) examined how people with ID negotiate Erikson’s (1950) stages. People with ID do not progress smoothly through the ‘Industry vs Inferiority Stage’ (6-12) where they begin learning new skills and developing knowledge. Peers become important in this stage and failure to resolve feelings of inadequacy can disrupt progress. This is in line with findings from Kenyon, Beail and Jackson (2013) in that the school years start to bring an awareness of being different to peers.
When children with ID transition to their teenage years, new challenges arise.
Differences that they may not have noticed before are exacerbated and individuals may experience an increase in stress as they have to come to terms with being ‘labelled’ (Kenyon, Beail and Jackson 2013).

Within these transition periods, adaptive functioning is required which can ensure that individuals can perform activities of daily living (Hayes-Hammer et al. 2000). People with ID may find transition challenging as they may have difficulties with reading, time management and visuo-spatial skills (Shessel and Reiff 1999). These could make everyday tasks anxiety provoking such as going to the bank; understanding letters and documents; and location finding (Shessel and Reiff 1999).

Transitioning into adulthood requires a certain independence (Mill, Mayes and McConnel 2010). The teenage years and early adulthood is a time when people with ID aim to increase their independence, such as gaining autonomy within their family (Mill, Mayes and McConnel 2010). Self-efficacy in gaining independence may be low for people with ID as they may expect that they will be restricted, experience a lack of inclusion and others may perceive that they were unable to represent themselves (Kenyon, Beail and Jackson 2013).

**Current Reviews**

Transition in ID has been the focus of many literature reviews. Some reviews have looked at research within education, for example the psychosocial impact of transitioning from primary to secondary school (Hughes, Banks and Terras 2014); enabling individuals with ID to complete post-secondary training, focusing on skills, training and information for school counsellors (Milsom and Hartley 2005); and predicting post-school outcomes (Alverson et al. 2010; Test et al. 2009).
These reviews do not consider opinions of individuals with ID. Cooney (2001) highlights the importance of giving people with ID a voice in research, allowing them to express themselves and display the capacity to make sense of their lives. There is a gap in the literature for a review looking at transitional periods from the perspective of the person with ID. The period from adolescence to adulthood is a significant time in development, as they will be striving for independence, but certain factors are becoming more apparent and can pose a barrier in the transition period.

**Aims of the Current Review**

The aim of this review is to gain an understanding of people’s experiences in the post-secondary transitional period into adulthood with a focus on further education, employment and voluntary employment. This period in an individual’s life is particularly significant, as it is a large milestone where independence is aimed for and people may begin to shape their identity. For people with ID, gaining independence can be difficult due to feeling as though they are different. Also, when transitioning from school to further education and employment, academic skills are important. Therefore, difficulties in these skills, such as maths and English, may be exacerbated. As a result, this period may be more challenging than for a person without an ID. This review would enable researchers to understand what is important to the individual themselves and help to develop further research around this. As the research in this area appeared to highlight this period of transition as a significant time in people’s lives, it is important to capture this to allow for the understanding of what factors are important to enable optimal opportunities and experiences. As the Social Model of Disability (Shakespeare, 2013) suggests that attitudes and opinions of society impacts opportunities and quality of life of individuals with ID, understanding what is important in this period for people with ID is essential for significant others and
services to be aware of. As a result, they will understand how to help people with ID develop to the best of their ability and help them to gain their own independence and sense of self.

The question underpinning this review was ‘What are the experiences of people with Intellectual Disabilities in the post-secondary transitional period?’

**Method**

**Search Terms**

A literature search was completed before the end of March 2017. The search terms were derived from the key words from other relevant papers and reviews. Searches were undertaken on PsycInfo, PsycArticles, Web of Science and Academic Search Premier. A manual reference search was carried out to identify further papers.

The search was carried out using the search terms related to:

**Intellectual Disabilities**

"mental* deficien*" OR "mental* handicap*" OR "mental* retard*" OR "mental* impair*" OR "mental* disab*" OR "mental* subnormal*" OR "learning disab*" OR "learning difficult*" OR "intellectual* difficult*" OR "intellectual* disab*" OR "intellectual* impairm*" OR "developmental disabilit*" OR “Pre$verbal” OR “Pre$lingual” OR “develop* dela*” OR “Special Needs” OR “special educat* students”

**The Transition Period**

"Transition*" OR "Chang*" OR "Develop*" OR "Life chang*" OR "School to work transition*" OR "social chang*" OR "adjust*" AND "post$secondary" OR "Employ*"
OR "supported employ*" OR "Higher Educat*" OR "Secondary educa**" OR "universit*" OR "college" OR "School" OR "Educat*" OR "inclusive educa**" OR "resident*" OR "vocation*" OR "special education needs/disabilit*" OR "Work experience" OR "Secondary special educa**" OR "outcome*" OR "secondary school" OR "future" OR "training OR Career*" OR "inclusive post$secondary" OR "job readiness" OR "job skills" OR "Occupation*" OR "unemploy*" OR "job change*" OR "job success" OR "mainstream education" OR "#High school" OR "independe*"

Experiences

"attitud*" OR "Experienc*" OR "narrative*" OR "event*" OR "Perspectiv*" OR "self$report" OR "life stor*" OR "life experienc*" OR "lived experienc*" OR "individual* perspectiv*" OR "case study"

School – leavers

"adolescen*" OR "juvenil*" OR "teen*" OR "youth*" OR "young people" OR "young person" OR "Adult*" OR "students" OR "special school leavers" OR "employees"
**Inclusion/Exclusion Criteria**

Table 1 displays the criteria which was applied to the papers:

**Table 1: Inclusion and exclusion criteria for the current review**

<table>
<thead>
<tr>
<th><strong>Inclusion</strong></th>
<th><strong>Exclusion</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Research undertaken from the point of view of both the individual themselves and the family/carers or from only the perspective of the individual with ID. The author considered family/carer perspectives to be of importance, as they would have been in close contact with the individual at the point of transition.</td>
<td>Included Autism Spectrum Disorder (ASD) as the primary diagnosis. ASD is not characterised by the same diagnostic criteria as ID(^1) (see Appendix B for ASD diagnostic criteria). Therefore, studies were included only when ID was the primary diagnosis. They were excluded if the studies included people with ASD as the primary diagnosis, or ASD alone.</td>
</tr>
<tr>
<td>Case studies as they may provide useful information on the lives of people with ID.</td>
<td>Family/carer perspectives only.</td>
</tr>
<tr>
<td>Peer reviewed research.</td>
<td>Dissertations</td>
</tr>
<tr>
<td>Qualitative research, as this would provide accounts of lived experiences.</td>
<td>Research looking at one specific transition programme.</td>
</tr>
<tr>
<td>Written in the English language.</td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) ID diagnostic criteria (5th ed.; DSM–5; American Psychiatric Association [2013]):

- Significant impairment of intellectual functioning
- Significant impairment in adaptive/social functioning
- Age of onset before 18
Included Studies

The literature search yielded a total of 18,726 papers. After applying the above inclusion and exclusion criteria, 11 papers were found to be suitable for the review (see Table 2). Relevant studies were identified by entering the search terms into four relevant academic search engines (see Figure 1). Limiters (papers written in English and qualitative papers) were applied to reduce the number of papers identified by the search. Title and abstracts were then examined for relevant key words, at this stage 1,715 papers were excluded. Seventy-eight records were then screened, and 11 duplicates were removed, leaving 67 full text articles to be assessed for suitability. At this point 60 papers were excluded. A manual reference list search was carried out on the remaining seven articles, four further papers were identified. This resulted in 11 articles being included in the review. Studies originated in the US (N=7), England (N=2), Scotland (N=1) and one paper did not specify the location.
Figure 1: Search Strategy

Web of Science (n = 2467)

Academic Search Premier (n = 5056)

PsycArticles (n = 4)

PsycInfo (n = 11,199)

Duplicates removed (n = 11)

Records screened (n = 78)

Records excluded based on title and abstract (n = 1,715)

Duplicates removed (n = 11)

Full-text articles assessed for eligibility (n = 67)

Full-text articles excluded, with reasons (n = 60)

Manual Reference list search (n = 4)

Studies included in qualitative synthesis (n = 11)
Quality Assessment

A quality assessment was carried out using an amalgamation of two existing checklists (National Institute for Health and Care Excellence [NICE, 2012]; STROBE Statement 2007 [See Appendix C]). The NICE (2012) checklist was for qualitative studies and the Strobe (2007) checklist was for cohort studies. These checklists were combined, as alone they did not consider all aspects which were required in measuring the quality of the included papers. The two measures combined allowed the researcher to thoroughly assess the quality of the appropriate aspects of the papers. This new checklist used selected items from both checklists and was piloted by the researcher to ensure that it enabled a suitable review of the literature.

All papers included were considered suitable for review based on their scores on each aspect of the paper (See Appendix D). For example, they were scored on aspects such as; the quality of information in the abstract, such as providing a comprehensive summary of the design and findings of the research; the suitability of a qualitative approach to fulfil the aims of the research; and the details provided of data analysis. Scores of ‘2’ were provided if the papers fit the criteria in full, ‘1’ for partly fulfilled criteria and ‘0’ if they did not fit the criteria. Papers were scored accordingly and the scores were calculated to create a percentage.

Data Extraction and Data Analysis

The researcher developed a tool to extract the data from the articles included in the review (Appendix E). The data extraction tool was developed for extracting data relevant to the research question. Data was analysed using thematic synthesis (Thomas and Harden 2008).
There were three stages in the analysis process, following data extraction using the data extraction tool. Firstly, the researcher made notes in the margins of initial ideas that were derived from the data. Extracted data was coded and initial themes were developed creating a deeper understanding of the experiences of people in the research papers. Themes were then collected into homogeneous groups to find common patterns within the data. This allowed for the data to be summarised, with an aim to answer the research questions presented.

Results

Characteristics of Included Studies

All the included papers aimed to examine the transition period from high-school to paid employment or post-secondary education. In addition, five papers investigated the role of parents, students and teachers in the transition period (Doren et al. 2007; Fullerton and Duquette 2015; Lindstrom et al. 2007; Morningstar 1997; Thoma, Rogan and Baker 2001), two investigated the social aspects of the transition period (Small, Ragavan, and Pawson 2013; Butcher and Wilton 2008), one investigated how students chose career paths (Morningstar 1997) and one study did not specify specific aims (Dyson, Meagher and Robson 2002).

All papers adopted a qualitative approach, six studies carried out interviews (Butcher and Wilton 2008; Connor, [2012] 2013; Small, Ragavan, and Pawson 2013; Thoma, Rogan and Baker 2001; MacIntyre 2014), two adopted a case-study design (Fullerton and Duquette 2015; MacIntyre 2014), one carried out observations (Thoma, Rogan and Baker 2001), two studies described their methods as ‘multiple methods’ including case studies, field notes, observations and interviews (Doren et al. 2007; Lindstrom et al. 2007). One paper reviewed documents (Thoma, Rogan and Baker 2001), one
carried out an informal meeting with the participants following interviews (Connor 2013). Focus groups were also used by Morningstar (1997) and one used ‘talking mats’ which were a medium in which the individual could use pictures and symbols to express themselves (Small, Ragavan, and Pawson 2013). Dyson, Meagher and Robson (2002), reported on interviews and case studies from a previously conducted large scale study.

All participants identified as having an ID, some self – identified with having ID (Connor [2012] 2013), others had a formal diagnosis/document ID (Doren et al. 2007; MacIntyre 2014; Lindstrom, Doren, Metheny & Zane 2007). Other studies did not specify whether the ID were self-identified or a formal diagnosis. Papers included participants with a range of ages (14 – 40 years), both male and female participants, and ranging in sample sizes (N= 2 – 76).
<table>
<thead>
<tr>
<th>Authors, Date of Publication and Location</th>
<th>Aims</th>
<th>Design/Methodology</th>
<th>Sample</th>
<th>Summary of findings and outcomes</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butcher and Wilton 2008, USA.</td>
<td>To examine the transition experience from high-school to paid employment and the social geographies.</td>
<td>Qualitative: Participant observations and in-depth interviews. Four participants were interviewed twice (summer after leaving school and six months later) Two had already left school and were interviewed once. The process of data analysis was not specified.</td>
<td>N= 6 (Four female, two males, age 19 – 29). Individuals with ID participating in a non-profit service organization. Parents and private sector employers.</td>
<td>Vocational Training – Helped with daily living skills, confidence building, social skills and provided something to do. Some participants moved onto supported employment in a mainstream setting, or sheltered workshops. Others were not ready or employment opportunities not available. Funding for additional training was not guaranteed. Sheltered Workshops – Social environment providing fun. Enabled people to develop independent skills. There was a lack of progression,</td>
<td>Moving onto competitive employment was rare. Successful transition may not be defined in terms of gaining employment, but transitioning to ‘meaningful activity’ such as recreation, volunteering etc.</td>
</tr>
</tbody>
</table>
| Connor 2012, USA. | To examine how students with ID manage the realms (social/academic etc.) through their first year of college. | Qualitative: Participants were interviewed three times, Interviews lasted 75 minutes. Data was analysed using a four-step process. Themes were identified and data was reduced and coded; themes were N = 3 (Two females, age 19 and 40, one males, age 19). College students self-identified as having ID. | more skilled people tend to stay long term as it is of benefit to funding for the company. **Mainstream** – Low pay or no pay, appeared to be of benefit to the companies. Separated from customers. Social isolation, difficulty securing employment or long – term supported employment. **Academic Realm** – Understanding own needs and the importance of the college meeting needs e.g. Having extra time, recognising strengths and taking small steps. **Social Realm** - Overall considered All participants experience similar difficulties but managed them in different ways. All of them were considered ‘active agents’ and were not deficit – focused. All approached the social aspects of college in different
<table>
<thead>
<tr>
<th>Connor 2013, USA.</th>
<th>To examine how students manage the demands of transitioning to college and if this</th>
<th>Qualitative: Interviews (N=3) lasting 75 minutes over a period of three months and attended</th>
<th>N=2 age 19 and 40. Both self-identified as having ID and experienced the transition to college.</th>
<th>Social class significantly affects the college experience of the two participants.</th>
</tr>
</thead>
<tbody>
<tr>
<td>organized into subcategories; data were then analysed in relation to the research question; data were then arranged for interpretation.</td>
<td>difficult, feeling socially isolated and finding it difficult to gain acceptance. <em>Emotional/ Personal</em> – Personal relationships and supportive families were deemed important. College caused some emotional distress, but also helped the acceptance and creating an identity. One participant took a break from college and considered moving colleges. The other two looked forward to continuing’.</td>
<td>ways, which may reflect their diverse backgrounds. All were proactive in creating an identity and recognising their strengths, thus, finding meaning in life.</td>
<td></td>
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<tr>
<td>Changes their thinking around their identity.</td>
<td>A final informal meeting. Data was analysed as with Connor (2012).</td>
<td>Strengths and limitations. <em>Identity and Learning Disabilities</em> – One participant considers ID as a minor part of who she is. In contrast, another feels that she has developed herself throughout studying with a ID. <em>Social Class</em> – One participant feels entitled to education and another feels like an ‘imposter’ due to social differences. One participant is continuing with college, one participant is currently tutoring students with doctoral degrees. ID and transition periods can be experienced in different ways.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Source</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Alterable personal factors</td>
<td>Programme factors</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------</td>
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<td>-----------------------------</td>
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<tr>
<td>Doren et al. 2007, USA.</td>
<td>To examine the ‘programme and alterable personal outcomes that may contribute to post-school outcomes’ (Doren et al. 2007, 172).</td>
<td>Qualitative: Multiple method, multiple case-study design. In-depth structured interviews, review of records, observations, and field notes.</td>
<td>N=13 (8 women and 5 men, median age – 23).</td>
<td>Alterable personal factors - ‘a) being proactive or goal oriented, (b) understanding the impact of one’s disability, (c) understanding the financial impact of one’s job or career choices, (d) having the ability to self-advocate, and (e) displaying prosocial coping skills’ (Doren et al. 2007, 175 - 176).</td>
</tr>
</tbody>
</table>
and supports that addressed the post school interests, goals, and needs of young adults.’ (Doren et al. 2001, 175-176).

12 in full or part time employment for at least a year prior to post school interviews.

<p>| Dyson, Meagher and Robson 2002, North-East England. | Not specified. | Qualitative: Reporting on semi-structured interviews. Some case studies were also used. Unsure of data analysis. | N=76 (aged 16-25) Former special school students recruited from another project ‘The Routes Project’. |
| Turbulence, transition and progression – A difference between transition and progression was noted. Transition was described as ‘the move from school to post-school activity’ and progression was described as ‘the move towards better circumstances’ (Dyson, Meagher and Robson, 2002). |
| There is not enough focus on transitions from school and students may need support following school. Resilience is also important in understanding post-school transition experiences. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fullerton &amp; Duquette 2015, location unknown.</td>
<td>To examine the post-secondary transition period and the interplay of the roles of parents, students with ID, and teachers from the perspective of the family.</td>
<td>Qualitative: Case studies. Data was analysed using a cross case analysis.</td>
<td>Purposefulness, Purposelessness, and personal problems – Personal characteristics and circumstances were attributed to student’s management of post-school activities. Unsure of outcomes specifically but most were reported to be involved in some form of post-school activities. Most of the students with ID were awaiting acceptance from a university or were employed or in post-secondary educations. Understanding the diagnosis and the strength and needs of the students was important in the transition process for the students.</td>
</tr>
<tr>
<td>Lindstrom et al. 2007, USA.</td>
<td>To examine two questions - ‘a) how are family structural variables (e.g. parental occupation, etc.) related to school outcomes, and ‘b) what is the role of the family in the transition from school to work?’</td>
<td>Qualitative: Multiple method, multiple – case studies. 59 In – depth, semi structured interviews</td>
<td>Role of Family Structure – SES was not directly linked to outcomes. Family structure and processes influence career development and post-school outcomes.</td>
</tr>
<tr>
<td>Education and Socio-economic status (SES) related to career development and professional outcomes.</td>
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<tr>
<td>b) How are family process variables (family involvement, support, advocacy and career expectations) related to career development and post-school outcomes for young adults with ID.’ (Lindstrom et al. 2007, 350).</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(over nine months, lasting two hours, 90 minutes). Data analysis as with Doren et al. (2007).</td>
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<tr>
<td>People in low SES families had an expectation on them that they would contribute to their families. They also expressed a desire to be different from their families.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Components of Family Processes – Relationships, family involvement, support and advocacy, career aspirations and expectations and engagement in career related activities all are related to career development and post-school outcomes.</td>
<td></td>
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<tr>
<td>Outcomes differed depending on group; Advocates – All in independent living and earning in high wage jobs.</td>
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</tr>
<tr>
<td>MacIntyre 2014, Scotland.</td>
<td>Investigating the experiences of young people as they make the transition from childhood to adulthood, with a focus on education, training and employment.</td>
<td>Qualitative: Case studies. Each participant was tracked for a period of 6 – 9 months. Interviews (N=2) with participants and significant others. Process of data analysis not specified.</td>
<td>N=20 (age 18 – 21) with moderate-severe ID.</td>
</tr>
</tbody>
</table>
| Morningstar 1997, USA. | Investigating how people choose careers and future employment and the role families play in this. | Focus groups lasting two hours. | 71 (nine focus groups, ages 14 – 21). | sustaining employment due to lack of support in the workplace.  
*Social Citizenship –* Inclusion was important, college and employment were deemed important for this. Not many socialised outside of college or the workplace. 16 went into further education, 4 obtained paid employment.  
*Identification of Careers and Future Employment –* A lot of participants considered future carers in very divergent fields. Careers chosen due to money and future economic; employment trends; experiences working; there were a number of factors that impacted on the career identification and aspirations of the individuals that participated in the study. |
vocational programmes did not have a large influence on chosen career paths.

*Other Life experiences* – Other life experiences influenced career aspirations.

*Family Influence* – Careers and occupations tended to be based on the careers that family members had. They also believed that their families could help them in finding jobs.

Outcomes unknown.

**Small, Ragavan and Pawson 2013, England.**

Investigating how social networks changed during transition from school to college.

Qualitative: Semi structured interviews (2 over a year). Talking mats were used.

N = 43.
Aged – 14 – 16 (N=12); 17 – 19 (N=12); 19 – 22 (N=11).

*Family* – Central in all cases. Mother was the main source of support.

Social networks, involvement in activities were limited. Transition planning should
<p>| School, Friendship and Leisure – Limited social networks and independent socialising. School was most important in providing social opportunities. |
| Feelings and aspirations about the future – Participants wanted to feel ‘normal’ and be involved in activities that non-disabled people were involved. Going to college and gaining employment was also important. There were limited opportunities and social networks declined. |
| Social Networks remained stable until the transition period. Most people attended a day centre, two |
| consider Exo and Meso systems. |</p>
<table>
<thead>
<tr>
<th>Thomas, Rogan and Baker 2001, USA.</th>
<th>To examine transition planning, focusing on student involvement.</th>
<th>Qualitative: Observation, in-depth interviews and document analysis.</th>
<th>N=8 (four males, four females aged 18-21). Beginning final year in high school.</th>
<th>people lost placements and therefore stayed at home for five months.</th>
<th>Meetings were controlled by adults and prepared at the convenience of the school, they were driven by the professionals and did not use a person centred manner.</th>
</tr>
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</table>

**Meeting Preparation**
– Parents and teachers in control of meeting preparation.

**Transition Meetings**
– Logistics of meetings were planned between the school and parents. Meetings were deficit focused.

**Communication Issues**
– Adults spoke to each other, students found it difficult to have a voice. Some professionals aimed to facilitate student involvement.

Much more positive outcomes than are
|   |   |   | typical for students with LD. |
Methodological Quality

All studies were found to be of good quality with scores ranging from 69% (MacIntyre 2014; Dyson, Meagher and Robson 2002) to 100% (Doren et al. 2007) with a mean score of 83% (See Appendix D). A qualitative approach was suitable to address the aims and research questions in all studies included.

The papers all included a clear abstract and provided a thorough description of the background, design and aims of the research being undertaken. Most of the studies gave a comprehensive account of the background to the research and provided a rationale; provided all key elements of the design of the study; provided a detailed and in-depth account of the stories told by participants and described key findings in the study with reference to the objectives described.

Dyson, Meagher and Robson (2002) and MacIntyre (2014) did not score as highly due to the lack of a substantial description of data collection, for example Dyson, Meagher and Robson (2002) provided information about the location of the research and some demographic details of their participants, but did not provide any further information. As their sample was recruited from a larger cohort, it appears that this information may have not been available. The researchers explained that data was collected from a pool of participants from a large-scale study, but no further information was provided. The researchers also did not provide details of the process of data analysis therefore it is difficult to comment of the reliability of analysis. A thorough description of the results was provided with recommendations and a description of the implications.

Macintyre (2014) omitted details of the outcome of the study in the abstract. They provided an account of the aims of the study, but did not state any specific aims, which means that it could be difficult to create conclusions in the discussion. They described their analysis as a case-by-case analysis and themes were derived from this, but more
detail could have been provided of the analysis process. No information was provided on the reliability or the limitations of the study, which could provide useful detail of further research and how to improve on the existing research.

Eight of the studies (Connor [2012] 2013; Doren et al. 2007; Fullerton and Duquette 2015; Lindstrom et al. 2007; Morningstar 1997; Small, Ragavan, and Pawson, 2013; Thoma, Rogan and Baker 2001) provided a full description of the analysis of the data. MacIntyre (2014) and Butcher and Wilton (2008) described some of the analysis but did not give comprehensive details of the methods used.

Three of the studies (Doren et al. 2007; Lindstrom et al. 2007; Morningstar 1997) had undertaken a reliable analysis of the data as more than one researcher coded the transcript and disagreements were addressed in this process.

Synthesis of study findings

Four main themes were derived from the data. These were; Transition; Influential Roles; Role of Students with ID; and Outcomes. All but one of these themes had a variety of subthemes (See Table 3).

Table 3: Superordinate and subthemes derived from the data

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transition</strong></td>
<td>Opportunities</td>
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<tr>
<td></td>
<td>Expectations and Choices</td>
</tr>
<tr>
<td></td>
<td>Experiences</td>
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<tr>
<td><strong>Influential Roles</strong></td>
<td>Role of Parents and Family</td>
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<td></td>
<td>Role of Society</td>
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<td></td>
<td>Role of the School/College/Workplace</td>
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<tr>
<td>Role of Students with ID</td>
<td>Self – Development</td>
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<td>-------------------------</td>
<td>---------------------</td>
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<tr>
<td><strong>Outcomes</strong></td>
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</tbody>
</table>

**Transition**

**Opportunities**

A wide range of opportunities following the transition from school were represented in the sample. Some aimed towards employment such as vocational training, sheltered workshops and mainstream workplace placements (Butcher and Wilton 2002), others went directly into competitive employment (Morningstar 1997).

Vocational training provided opportunities for students prior to leaving school and school leavers to help them with job skills, social skills and assessments. Sheltered workshops offered workplace skills to encourage them to move on to a ‘real life’ workplace. Opportunities in a mainstream workplace followed the vocational training programme, such as working in cafés and hairdressing. These were offered through supported employment, through the organization or as competitive employment (Butcher and Wilton 2008).

Post-secondary education was mentioned in four studies (Connor [2012; 2013; Morningstar 1997; Dyson, Meagher and Robson 2002; MacIntyre 2014). MacIntyre (2014) suggested the amount of people attending further education was larger than was expected in the general population. They suggested that the reason for this was students attending a ‘School Link Programme’ which provided a taste of life in college. They also all had attended placements, training schemes and supported employment to gain an experience of working life.
Unfortunately, a third of Dyson, Meagher and Robson’s (2002) sample had been unemployed and 10% described themselves as doing nothing. They also suggested that students move through a range of activities following high school. In their sample, on average, students had been involved in two to three activities. It appears the reason for this may be that they become stuck in a ‘revolving door’ whereby they need to keep themselves moving to continue being eligible for benefits and allowances, thereby demonstrating a lack of choice in post-school activities.

*Expectations and Choices*

In some cases, parents appeared to expect more from the choices their children made. For example, in Butcher and Wilton (2008) parents felt that attending an organisation that catered to people with ID was an easier option than attending mainstream settings. Parents expected that their children followed paths like their own, onto post-school education and then employment (Fullerton and Duquette 2015). Although this could be due to families feeling that their children were not ready for the adult world and encouraged them into post-school education to build experience (MacIntyre 2014).

On the other hand, some parents did not expect their children would be able to find a job or go to college due to their ID (Lindstrom et al. 2007). A parent in one sample believed that their child was incapable of doing work at school independently and expected the school to provide them with help (Fullerton and Duquette 2015).

Regardless of the difficulties experienced in the transition process, students still appeared to be optimistic (Dyson, Meagher and Robson 2002) with 68% of their sample expecting to be in full time employment within the year. This was also reported in Small Ragavan and Pawson (2013), along with the wish to attend college; live
independently; be married; travel; learn life skills, and have the ability to do the activities that non-disabled peers can do.

There were a variety of reasons for students choosing specific career paths (Morningstar 1997). Some people chose based on the money that they expected that they would earn in a career. Although, it was thought that these expectations were not realistic or very well informed. Having the opportunity to attend vocational training and learn about career options allowed people to gain experience to inform choices. Finally, family and experiences also impacted career choices, they chose careers based on those members of their families had (Morningstar 1997).

**Experiences**

Students enjoyed school and felt it provided the skills and confidence to make future decisions (Dyson, Meagher and Robson 2002). Although there were some reports of negative experiences, for example not feeling respected by teachers; feeling like they were not considered as people; and that there was a lack of support in enhancing their learning (Dyson, Meagher and Robson 2002). It was reported that being in a ‘special’ school could exacerbate the feeling of being different (Small, Ragavan, and Pawson 2013).

Difficulties were experienced within the transition period with power imbalances arising. Trying to get voices heard was an issue for students as they described a ‘struggle’ to resolve difficulties with adults. (Doren et al. 2007). A similar experience was recorded in Thoma, Rogan and Baker (2001) whereby students seemed to be the hidden voice in transition planning. Students were not engaged in transition planning activities to the same extent as their parents and teachers due to the use of jargon and lack of inclusion in meetings. This suggests a power imbalance in the meetings, as the adults took control, resulting in students feeling that they were not treated like adults.
An issue of equality in the workplace arose as it was reported that one worker in Butcher and Wilton’s (2008) sample was not paid and another was paid a third of the minimum wage. They also experienced segregation as workers were separated from customers as managers did not want someone who looked like they had a learning disability serving customers (Butcher and Wilton, 2008).

The transition to college also came with difficulties. One student’s experience was described as “sheer trauma” becoming a “survivor” in “Hell.” (Connor 2012, 1020). During his time at college, this participant experienced depression and felt exposed. He was not accepted in his student halls and had a very difficult experience (Connor 2012). These difficult transition experiences were mirrored in Connor (2013). One student had studied for 14 years due to low confidence which lead to issues such as addiction to drugs, food and alcohol.

The transition period was not all negative. One student in their study was happy with her school and her placement (Dyson, Meagher and Robson 2002). However, this was the student’s first placement, and the researchers suggest that this could be due to the placement providing her a taste of the working world. They suggest that she may struggle to find employment in the long term, as the training did not offer specific skills development. This reflected the experiences of two other participants in their study.

**Influential Roles**

*Role of Parents and Family*

Parents had key roles in the transition stage such as transition planning, advocacy (Fullerton and Duquette 2015) and instilling key values (Thoma Rogan and Baker 2001). Parents took control in the transition stage by assisting children in making
formal transition plans as they did not feel that their schools were active in this (Fullerton and Duquette 2015). They also played a large part in setting transition goals and speaking to the school teachers in transition planning meetings. There was some evidence that students relied on parents to make decisions for them (Dyson, Meagher and Robson 2002). Advocacy was a key role for parents, with this role being taken predominantly by the mother. This advocate role decreased as children grew older and parents allowed them to take responsibility (Fullerton and Duquette 2015). Parents passed on their values of hard work, determination and independence (Thoma, Rogan and Baker 2001).

The family was a large source of support, particularly emotional, practical support and personal development (Small, Ragavan and Pawson 2013; Connor 2012). Social economic status (SES) of the family influenced post-school outcomes. In lower SES families, it was suggested that the family fuelled an ambition to succeed as they did not want to become like their families (Lindstrom et al. 2007).

Relationships within the family varied between participants. Some relationships were positive, others were strained as parents struggled to provide support or had rigid boundaries. Other factors impacting post-school outcomes were involvement within the family; advocacy; career aspirations and expectations; and intentional career related activities (Lindstrom et al. 2007).

Role of Society

Social class and background may play a part in how individuals manage the transition period (Connor [2012] 2013). All the participants came across similar difficulties in Connor’s ([2012] 2013) papers but all managed them in different ways. For example, one student described herself as feeling like an impostor in college and whereas the
other came from society where going to college and succeeding was the norm, therefore felt as though college was inevitable (Connor 2013). Connor (2012) felt that this reflects the Social Model of Disability (Shakespeare 2013) in that the attitudes of society impact on the opportunities available.

In Butcher and Wilton (2008) it appeared that in vocational training and sheltered workshops importance was placed more on the social aspects of the training. Sheltered workshops were described as fun being with friends and participants could hug other members and their supervisors. The opposite was found in the college environment (Connor 2012). The social aspect of college was overwhelming to some students, one student described there being too many people to make friends with although it did not appear that this person felt socially excluded in this instance. Another described academic work being of most importance having no time for socialising, whilst another felt socially excluded and therefore moved away from the college dorms to his parents’ house.

School, college and the workplace was important in creating social relationships as few people socialised outside of the workplace or college (MacIntyre 2014). It was often the case that people were not able to socialise independently, therefore social networks were limited. Once people left school, these social networks began to break down, which could eventually lead to social isolation (Small, Ragavan, and Pawson 2013).

Inclusion and belonging was identified as a key factor in finding a place in the community and feeling like everyone else. Being treated like an equal and an adult and having a uniform, taking home a wage and calling lecturers by their first names all contributed to this sense of inclusion (MacIntyre 2014).

*Role of the School/College/workplace*
The school had a role in transition planning but it appeared that transition planning meetings were driven by the professionals and organised at their convenience. However, some teachers adopted the role of empowering students in the process by facilitating information sharing, acknowledging and responding to non-verbal cues such as body language and eye contact (Thoma Rogan and Baker 2001). Teachers provided mentoring and provided support throughout transition and enabled the development of self-determination and self-advocacy. The role of teachers did not appear to be as significant as the parents’ role although the teacher/student roles remained stable, parent/child roles changed over time (Fullerton and Duquette 2015).

Along with self-determination and advocacy, resilience is a skill that can be developed and is important in positive post-school outcomes (Dyson, Meagher and Robson 2002). The school can play a part in developing resilience by ensuring positive relationships between students and teachers, and enabling students to develop personal attributes.

Collaboration with other services is a significant role adopted by the school. For example, the Connexions service aims to provide young people (13-19) with guidance in the post – secondary transitional period to help them prepare for employment (Department of Education and Skills, 2004). Schools could aid students in accessing targeted services which contributed to post school outcomes, however this was only effective if students engaged with these services (Doren et al. 2007). Targeted services were described as services which were consistent with the needs, interests and goals of students and provided experiences such as courses, activities to help individuals learn further about careers, training and job placements (Doren et al. 2007).

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2 Connexions service aims to provide young people (13-19) with guidance in the post – secondary transitional period to help them prepare for employment (Department of Education and Skills, 2004)
The role of college was not largely discussed in the research but it was suggested in Connor (2012) that helping students recognise and utilise strengths and ensuring that they meet students’ needs provided psychological support.

**Role of Students with ID**

**Self-Development**

The sheltered workshops and the vocational training helped develop skill which enabled participants increase their independence, such as learning to make their own lunch, do household tasks and encouraged them to get the bus to placements (Butcher and Wilton 2008).

There were also many characteristics mentioned within the studies that students developed for successful post-school outcomes. These were, resilience (Dyson, Meagher and Robson 2001); self-awareness (Connor 2013; Fullerton and Duquette 2015); self–determination (Connor 2013; Dyson, Meagher and Robson 2001; Fullarton and Duquette 2015); having a desire to learn; and seeing value in the opportunities that they were given (Dyson, Meagher and Robson 2001).

In addition to these characteristics, Doren et al. (2007) suggested that alterable personal factors related to a positive transition period. These factors were described as the individual taking control of their own transition and working towards goals that they have set. They would also be able to be an advocate for themselves and have prosocial coping skills.

**Being Proactive**

It was demonstrated in Connor (2012) that individuals managed difficulties in different ways but they were all proactive. All of them focused on their strengths and acted accordingly. This was reflected in Connor (2013) in which he suggested that students
facilitate their own success by their own actions and choices. Students in the study attended extra classes and set themselves goals to improve on areas in which they felt they were weaker and made use of all support available. Similarly, Doren et al. (2007) found that being active in aiming to reach goals and being aware of the earnings and advancement opportunities in careers led to more positive post-school outcomes.

*Outcomes*

In three of the papers (Doren et al. 2007; Lindstrom et al. 2007; Thoma, Rogan and Baker 2001) the type of employment varied, with some individuals in full time employment and others in part – time employment. Pay varied with some in high wage jobs and others in low skilled/low wage jobs. It was thought that this may have been influenced by parental involvement in the individual’s upbringing (Lindstrom et al. 2007). Unfortunately, this employment was not always consistent with the goals that individuals set (Thoma, Rogan and Baker 2001) and some found it difficult to maintain employment (Lindstrom et al. 2007).

Butcher and Wilton (2008) found that there were limited options for competitive employment in all areas, with limited opportunity to progress. They also question whether employment was a goal for the individuals in the study or whether they were more interested in activities that were meaningful to them, such as recreational activities.

Others moved on to further training such as college and universities or onto youth training programmes (Dyson, Meagher and Robson 2002). In Connor ([2012] 2013) some were looking forward to continuing college, whereas one participant was taking a break and considering moving college due to the difficulties experienced at college.
Living arrangements following school varied also in Lindstrom et al (2007), some people were living independently or with partners/spouses, whilst others stayed at home with their families. Some of the individuals living independently continued to need financial support from parents.

**Discussion**

The present review aimed to examine the experiences of the transition period from school to post-school education, employment and voluntary employment from the perspectives of people with ID. All papers adopted a qualitative design and were rated of acceptable quality. All papers included the perspective of individuals with ID, and most of them also included the perspectives of significant others, including parents and teachers.

Initially there appeared to be a variety of opportunities for people with ID following high school. Unfortunately, following these opportunities further progress did not seem to be easy for these individuals to make. People may not be ready for employment or the option of employment may not have been available. The employment that was available was not always stable. There was also the suggestion of being stuck in a ‘revolving door’ in that people may not be eligible for benefits if they moved on. This supports the suggestion for Cooney (2001) that transition is not a linear process and people are not able to progress from one activity to another. Despite this lack of progression, it was reported that people with ID remained optimistic and expected that they would progress in their goals.

The transition period was difficult for some individuals; some found it difficult to get their voice heard as there was a power imbalance which reflected adult control in the transition planning process. Other difficulties included not being able to fit within the workplace with others, at times being hidden away from customers due to shame by
employers. At times, they were also discriminated against in terms of pay, being paid less than other workers or not being paid at all. This reflects the Social Model of Disability (Shakespeare 2013) in that attitudes of members of society impacted opportunities.

Parents played an important role in transition planning and being advocates for their children. Interestingly, the most successful individuals were encouraged by their parents to begin to be independent. This is demonstrating the individuals moving through Erikson’s (1950) stages, at the age where they would be in the ‘Identity vs Role Confusion’ stage (12 – 18). Encouraging adolescents to create their own identity and choose their own paths results in a more successful transition and moving onto the next developmental stage.

Consistent with previous research (Bremell, Kachgal and Schoeller 2003) developing self-determination lead to successful post-school outcomes. School and employers can help in developing and sustaining self-determination (Bremell, Kachgal and Schoeller 2003). Resilience and self-advocacy were also key factors in successful post school outcomes in the current review. Resilience can be developed from a young age according to Millar (2002) in helping children manage relationships in school, for example understanding how to cope when friendships breakdown and how to maintain friendships; helping children to reframe negative situations i.e. see them in more positive light; and helping them identify strengths.

Although the review aimed to examine the experiences of people with ID themselves, there was a lack of available research focusing on the experiences of individuals only. As such, the views of others were considered, as the researcher felt that if these were avoided, useful information may have been lost. It was clear in the review that schools and parents took a prominent role in the period of transition. As a result, it is important
to approach these findings with caution and an awareness that the opinions of others may have influenced the ability for people with ID to have their say, as it has been suggested that people with ID may struggle to get their voices heard. This may be reflected throughout the review, due to the inclusion of the opinions of others.

**Limitations**

There were some limitations to this review. Firstly, the search terms were wide and therefore the researcher had to be strict with the exclusion criteria to avoid being unable to meet the aims of the review. As a result, there may be useful information, for example, understanding the usefulness of specific programmes in transition planning, that were not included in this review. Secondly, the sample size was small, with only 11 studies being reviewed, therefore it may be difficult to generalise these findings to the wider population of people with ID.

Thirdly, it included perspectives of significant others, due to the lack of available data on the experiences of people with ID alone, and therefore does not give a true account of the individual’s experience alone. As discovered in the review, the transition period is led by parents and teachers most of the time and therefore including studies that were also from the perspective of the adults may have resulting in a biased view of the transition period. On the other hand, including the views of others may have provided an insight to the amount of input of the students, which may have not being clear without including the perspectives of students.

Also, most of the studies were located in the USA, therefore, the results may not be transferable, as the processes involved in transition may be different across countries. Therefore, the conclusions made from this review may be limited to a specific population. The researcher is unable to comment on the differences in the transition
process between countries at this time. As a result, this may be an area for future research.

Finally, the researcher should have included a second opinion when rating the methodological quality of the studies to increase the reliability of the scores.

**Further Research**

This review investigated experiences of the transition period from the point of view of the individuals. Further research could look at aspects in specific programmes and transition planning activities which were most effective in this stage of an individual’s life. It may be useful to carry out a review excluding perspectives of significant others as they may have a biased opinion.

To gain location specific information on the process of transition, further research could focus on specific countries to gain an understanding of differing experiences of transition. Comparisons may be made between locations to examine contributory factors to the most successful transitions.

**Conclusion and Implications**

The results from this review support existing research that transition periods can be a challenging time for adolescents with ID. The options are limited at times, and individuals may become stuck in a ‘revolving door’ without a chance to break free and progress. Individuals struggle to get their voices heard in this process as parents and teachers may feel that they are not capable. Therefore, at times, they do not have a well-informed idea of the reality of going into the working world.

Services, parents, and schools can take from this research the knowledge that they should facilitate the growth of self-determination, resilience and encourage self-advocacy to enable individuals to express their opinions and take a lead role in the
transition process. They would be able to do this by helping them to prepare for the adult world by asking what support individuals need and want in this stage. Therefore, allowing individuals to take control and achieve their own goals, which would help them to grow in confidence and gain independence for the future. Although, it must be recognised that these findings must be interpreted with caution, due to the possibility of bias as the perspectives of others have been taken into account.
References


Part 2: Empirical Paper

This Paper is written in the format ready for submission to *Disability & Society*. See Appendix A for submission guidelines.

Total word count: 7994 (excluding abstract, tables, references and appendices)
Personal Experiences of Living with an Intellectual Disability: Approaches and Outcomes based on A Dual-Systems Model

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Abstract

People with Intellectual Disabilities (ID) face challenges within their lives, such as feeling different to others, being labelled, and difficulties with daily living. Difficulties may be exacerbated by society’s views. The aim of the current study was to examine the difficulties people with ID face and how they manage these, utilising theories from Second Wave Positive Psychology and a Dual – Systems Model. Using a qualitative approach, semi-structured interviews were carried out with nine adults with ID. Interviews were transcribed and data was analysed using Interpretive Phenomenological Analysis (IPA). Three main themes were ‘Identity’, ‘Managing life’s difficulties’ and ‘Approaches to life’. Findings suggest that people with ID face everyday difficulties, but these may be exacerbated by the ID. People find positivity in ID by accepting life and not dwelling on difficulties, but also being aware of limitations to set realistic goals and strive towards living a value-led life.

Keywords: Intellectual Disability, Lived experiences, day-to-day life, second wave positive psychology, approaches, challenges, difficulties.
Introduction

**Intellectual Disabilities**

There are criteria to be met to be formally diagnosed with an Intellectual Disability (ID). These criteria are adopted by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association [2013]) and the *ICD-10* Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines (World Health Organisation 1992). These are:

- Significant impairment of intellectual functioning
- Significant impairment in adaptive/social functioning
- Age of onset before 18

The British Psychological Society (BPS, 2015) also adopts this criteria for the formal diagnosis of an ID. The BPS highlights the importance of diagnosis to help people receive the support that they need, but also recognises that ‘labelling’ can be challenging for people.

**Living with an Intellectual Disability**

*Challenges*

People with ID face challenges throughout their lives. Difficulties typically start to be recognised when a child begins school. They may consider themselves different to other children as they sometimes need extra academic support (Kenyon, Beail and Jackson 2013). These differences in levels of ability may not be significant in younger
children as they are not expected to complete challenging work and are provided a lot of support by teachers (Connors and Stalker 2007).

Bullying is commonly reported by children with ID (Polloway, Shewel and Patto 1992; Connors and Stalker 2007; Purdue et al. 2011). Polloway, Shewel and Patto (1992) suggested some individuals experienced name calling and inappropriate comments which impacted on their self-esteem. Connors and Stalker (2007) reported that children felt that they were talked down to, stared at, given extra sympathy and have difficulty accessing leisure facilities and clubs. Due to bullying, individuals felt socially excluded and isolated (Purdue et al. 2011). These difficulties were carried into adulthood (Shessel and Reiff 1999) as they may have been isolated from peers at work.

The transition to adolescence and adulthood brings its own challenges, being diagnosed with an ID caused more stress and difficulty in the teenage years (Kenyon, Beail and Jackson 2013). Kenyon, Beail and Jackson (2013) asked people with ID their experiences of being diagnosed. Within the transition period to adulthood, there was a growing awareness of being different and having the label of ID emphasised these differences. Individuals felt that the label separated them from ‘normality’ and they were not perceived as equal to others. Ferguson, Jarret and Terras (2010) found that due to this perception of being different, they felt that they had a lack of choice and opportunity, particularly in health care as others did not perceive them as being capable in making their own choices.

Shessel and Reiff (1999) found that in adulthood, activities of daily living present challenges for an individual with ID. Difficulty reading can result in tasks, such as going to the bank and understanding letters, being anxiety provoking. People may find
themselves being late or getting lost due to time management and visuo-spatial difficulties. This resulted in elevated levels of stress and anxiety.

**Coping**

Despite the challenges faced, people with ID find ways to overcome them. They can adapt to make use of their strengths (Polloway, Shewel and Patto 1992) for example, they might find jobs that do not require reading such as building and using computers. This is known as the adaptation argument; people may be accepting of aspects that they find difficult and chose to focus on their strengths (Bognar 2015). Bognar (2015) suggests that adaptation is useful as people may be goal directed and motivated to learn new skills that are consistent with their strengths. People may also be able to compensate for things they cannot do by enhancing their abilities in other aspects (compensation argument [Bognar, 2015]). Other ways to cope included distancing selves from other’s perceptions, for example, ignoring negative comments (Kenyon, Beail and Jackson 2013).

**Attitudes Towards people with ID**

There are factors that can impact the quality of life for individuals with ID, one of these is the attitudes of other people. The Social Model of Disability (Shakespeare 2013) suggests that disability is socially constructed; society, values and opinions play a part in defining what disability is. Attitudes surrounding disability can have an impact on the treatment an individual with a disability receives from people in society. Thus, impacting the opportunities that are available (Shakespeare 2013). Due to this, Shakespeare (2013) suggests that if attitudes of society are changed, the discourse surrounding disability could be changed.
Despite growing awareness surrounding disability, for example the introduction of equality legislation and initiatives to improve opportunities (Appendix F), there are still negative attitudes towards people with ID (Scope 2014). Online surveys conducted between 2013 and 2014 suggested that over half of the British population felt uncomfortable talking to a person with disabilities; 21% felt unsure of how to communicate with a disabled person, therefore avoided talking to them; 36% felt that people with disabilities are not as productive as others (Opinium 2013; 2014 as quoted by Scope 2014). Attitudes towards ID, lack of opportunity, stigma, and discrimination can exacerbate the challenges in the lives that people with ID may face (Shakespeare 2013).

Shakespeare (2013) suggests that impairment should be accepted, which would change the experience of people with disabilities, as they would be enabled rather than disabled. Therefore, stigma and discrimination would be reduced and individuals would be able to reach their potential by having the same opportunities as an individual without an ID.

A key question is ‘Is disability just mere difference?’ (Bognar 2015, 46). As the Social Model of Disability (Shakespeare 2013) suggests that disability is a social construct and can be changed, it appears that it would be in line with the view that disability is ‘mere difference’. People may recognise that disability can result in limitations on life, but these limitations can be exacerbated by views of society (Bognar 2015). On the other hand, Bognar (2015) states that some disability is extremely life limiting, therefore even if society was accepting of this, the disability would still be present and life limiting.
Aims of the Research

The aim of this research is to explore any challenges in the lives of people with ID and to understand how people have approached positive and negative aspects of their lives. Having an awareness of how these challenges are approached may aid in understanding the aspects that contribute to a ‘positive’ life. There are gaps in existing research for investigations into the perspectives of people with ID. Much of the research includes perspectives of significant others, such as parents and siblings. Research from the perspectives of people with ID is important because it enables a first-hand account of what it is like to live with an ID and excludes the potential bias of other people’s opinions and attitudes.

Similar research has been carried out by Shessel & Reiff (1999), but as this research was carried out nearly 20 years ago, we are aware now that policies have changed, therefore this may have had an impact on the experiences of people with ID. Also, much research focuses on the negative aspects of living with an ID, whereas the current study utilises theory from Second Wave Positive Psychology. This is a relatively new field of study, therefore there is no research in ID from this perspective.

Theory from Second Wave Positive Psychology (Wong [2011] Appendix G) and a Dual-Systems Model (Wong [2012] Appendix G) was utilised as a guiding framework for creating the interview schedule.

Research Questions

The study aimed to address the following research questions:

- What is day to day life like for people with an ID?
- What are the positive aspects in life for people with an ID?
What challenges does a person with an ID face in their day to day lives?

How do people with an ID approach day to day life, and what were the outcomes of these approaches?

**Method**

**Design**

Qualitative data was gathered via semi-structured interviews with individuals with ID. Interpretive Phenomenological Analysis (IPA, Smith, Flowers and Larkin [2009]) was used to analyse the data. IPA is a method of gaining a rich source of data exploring lived experiences, focusing on what is like to be a human being, all the aspects that are important in our lived experiences, subjective experiences and social cognitions. It also focuses on how the participant creates meaning in their lives in terms of events that happen and their interactions with the environment (Biggerstaff and Thompson 2008).

**Participants**

Nine participants, four males and five females, aged between 31 and 60 were recruited from services within the Yorkshire and Humber region of the UK, including a supported living service (N= 2) and a charity (N=7). The charity aims to improve the lives of people with ID, providing teaching and training to enable them to develop skills and independence, giving them the opportunity to contribute in their community. Participants self-reported that they had an ID and were selected according to specific criteria. They were required to be aged 18 or over, able to communicate verbally and have the capacity to give fully informed consent.

**Procedure**
Ethical approval was granted by the Faculty of Health and Social Care Research Ethics Committee at the University of Hull in March 2017 (Appendix H). Following ethical approval, supported living services, day services and charities were contacted to gather interest in the study. If the services consented, service managers were provided with posters (Appendix I) to distribute within their service. The researcher visited services where possible, to speak to service users about the study. Potential participants were given the options of contacting the researcher directly (a contact number and email address was provided), or speaking to the manager or member of staff at their service who could inform the researcher of their interest.

Once interest was gathered, the researcher organised an initial meeting with participants to provide them with information sheets (Appendix J) and explain the processes that were involved in the research. Meetings were either at the participants’ homes, or at the service that they were recruited from. This depended on the most convenient location for the participants. Staff supporters were required to attend the home visits, but participants were given the choice of having them in the room whilst the interview was taking place. One participant chose to have a supporter in the room during the interview. A second meeting was then offered to complete the interviews. Some participants chose to complete the interview at the first meeting, whereas others chose to have the interview in a second meeting. The interview schedule (Appendix K) was developed with the Dual-Systems Model in mind. The schedule was piloted by an individual with ID and reviewed by the research supervisors prior to the interviews.

Before the interviews, participants were asked to fill in a consent form (Appendix L). In the instance that a participant was unable to read the information sheet, an audio information sheet was provided. Participants were required to provide their initials on the consent form. Following the interview, participants were provided with contact
details of services that could provide support (Appendix M) in the event of emotional
distress arising from the interview.

**Data Analysis**

Data was analysed using the principles of IPA (Smith, Flowers and Larkin 2009). The
interviews were first transcribed and then read several times. Notes were made in the
margins to record initial ideas (Appendix N). Transcripts were coded on three levels; a
descriptive level, focusing on the content of the interviews; a linguistic level, analysing
the language used by the participants; and a conceptual level, aiming for a deeper
understanding of the interviews. Emergent themes were derived from the data, and
superordinate themes were developed using abstraction to establish connections across
subthemes (Appendix O). Finally, all transcripts were analysed to find connections
across the subthemes.

In the process of data analysis, the researcher was aware of the value of her own stance
(See Appendix P). The constructivist stance is in line with the belief that knowledge is
a product of people’s experiences (Gillet 1998). In contrast, a positivist stance
considers that there is truth in knowledge based on scientific evidence and fact (Comte
1865). The researcher considered herself to be in agreement with neither of these
extremes within this research, but sees value in both stances. The aim of the research
was to gain perspectives of people with ID themselves and recognising that the
meaning they make of life will be derived from their experiences, but also not
devaluing the importance of the diagnostic criteria for ID. By considering these
perspectives, it is important in IPA that the researcher is aware of their own beliefs and
attitudes, which will be derived from their own experiences, but also not to undervalue
the meaning of ID to the people who are living with it. Therefore, the researcher’s
interpretation of the data, is an important aspect of IPA because it is thought that our
experiences in the world are always in relation to something else, therefore it is perspectival (Smith, Flowers and Larkin 2009).

The research supervisors read transcript excerpts to check the quality of the analysis, their opinions were considered in the analysis. They first gave the researcher direction onto the process of beginning analysis, following this they reviewed and added initial notes and provided advice on the narrowing down themes. The researcher attended several qualitative research groups to expand knowledge on qualitative analysis.

Results

Three main themes were derived from the data (Table 1) all of which had two subthemes. Pseudonyms were used to ensure participant confidentiality.

Table 1: Superordinate and subthemes derived from the data.

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td>Identity</td>
<td>What is ID?</td>
</tr>
<tr>
<td></td>
<td>I am Different</td>
</tr>
<tr>
<td>Managing Life’s Difficulties</td>
<td>Coping</td>
</tr>
<tr>
<td></td>
<td>Support and Relationships</td>
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<tr>
<td>Approaches to Life</td>
<td>Growth</td>
</tr>
<tr>
<td></td>
<td>Positivity</td>
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Identity

This theme focuses on how people create an identity with an ID. The theme includes two subthemes; ‘What is ID?’ explores the meaning of ID and challenges individuals may encounter. ‘I am Different’ explores how people may feel separate from other people without an ID. Some people described feeling ‘special’ and a ‘them and us’ perspective arose in the interviews.
What is ID?

Two participants described ID in diagnostic terms. Ian explained that he had ‘a mild learning disability’; Steven explained ‘my learning disability is a range of things, I’ve got Asperger’s syndrome, and I’ve also got a little bit of autism as well’; Jade explained ‘it’s a bit like a mental disability’. It appears here that participants did not have a full understanding of the meaning of these words, as they did not elaborate on what they meant to them. This could be reflecting a power imbalance between themselves and professionals using diagnostic terms. Therefore, individuals may be using words that they have been told, with no full understanding of what they mean.

Participants spoke about academic difficulties that they encountered, such as Maths, English, reading and writing. These difficulties make activities of daily living, such as money and budgeting challenging. Others spoke about difficulties such as keeping appointments and talking on the phone. Charlotte explained:

‘(life with ID) It’s just... harder... because none of the people, they doesn’t know what it’s... it’s like’ – Charlotte.

Many individuals had felt that they had lost control at some point of their lives:

‘they knew and were aware of my disability, so they changed all my classes but, I wasn’t happy about that, because some of my classes I understood and they... and they took me out of the best science class, and made me go into another science class’ – Steven.

Steven had his choice taken away from him because of the diagnosis. This is again reflective of the power imbalance and a loss of control. He perceived this as a negative impact on his life as he felt happy in the classes that he was previously in, and felt
upset at the school for taking this away from him. For others, it was the assumption that they would not be able to gain employment that represented a loss of control:

‘I don’t think I’d get a job, ‘cos I feel like it’s hard for me to go get a job’ – Charlotte.

Although, this may be reflecting a self-fulfilling prophecy. If Charlotte does not believe that she can get a job, it could be useful to consider whether she is taking the steps to try and get a job. If not, she is falling into the trap of not being able to gain employment, as a result maintaining the belief that she will be unable to.

Many people focused on difficulties that were not in line with the criteria for a formal diagnosis, suggesting that ID was not the most significant difficulty in life. Several people spoke about physical difficulties that they encountered. For example:

‘the disability I have... erm... oh what do I have... erm... I’m good at walking...but sometimes...I tend to lose my balance sometimes...” and “I err... suffer from asthma... I’m asthmatic.... so... I’ve always got to take my asthma pump...erm... like morning and night....and I take my other tablets as well before I go to sleep... which is erm... always the ones I get from the doctors...that’ll always help my chest a little bit and what have ya...’ – Rachel.

This quote from Rachel suggests that she does not have a real understanding of what her ID is. It appears again, that she has been told the diagnostic words, but is unable to find them, instead she talks about things that are difficult for her. This could be due to perceptions that ID must be difficult, therefore Rachel chooses to talk about things that are difficult for her.

Physical difficulties were sometimes exacerbated by everyday difficulties that people encountered. Jade explained that she had previously been in an accident, the injuries
she sustained due to the accident compounded the difficulties she had because of her ID. She described her ID as manageable if she had not had the accident, as she was required to plan daily life more than she did prior to the accident. Again, this may be a perceived lack of control over her life, but this time is not related to ID but to her accident.

Others spoke about typical everyday difficulties such as getting on the bus and not being able to connect to WIFI, which is an inconvenience that could be experienced with or without having ID.

Age related difficulties appeared to exacerbate the effects of ID:

‘Yeah health problems, I know I’ve got (name of family member) but I can’t help him very much these days. I’m too old for that ha-ha I’m too old ha-ha’ and ‘my illness stumped me ha-ha... yeah, did something to me and that, I just can’t concentrate very much’ – Nathan.

Although Nathan laughs throughout his interview, it appears that there is a hidden sadness behind the laughter, as he feels like his life is over and maybe not lived the fulfilled life that he would have wished for.

Some people spoke about what ID means to them.

Nathan spoke about having an ID for a ‘long, long time’ but no one was aware of it. As he was an older gentleman, this may have been reflective of the knowledge around ID at the time. This highlights the importance of widening understanding about disability in the general population.

Becky found it difficult to create an identity for herself with an ID. The everyday difficulties that she experienced was a constant reminder that she had an ID and consequently felt different to others:
‘I think it’s hard for me, erm... err... sometimes deep down I think, I’m err, I’m normal, and I feel like I’m in erm... someone else’s body, but deep down... well I know I’m in my own... feels like... like someone’s in it that’s trying take over my... over my life know inside, I’ve got a disability....’ - Becky.

In some cases, life factors other than having an ID created a barrier to creating one’s own identity. For Nathan, having a caring role for members of his family from an early age resulted in him not having time for himself and having chance to understand his ID. Therefore, he may have not been able to create meaning of his ID for himself, it appears that this resulted in him identifying with the role of a carer more than an individual with an ID.

Some showed acceptance of their ID’s and embraced it as a part of their identity, it seemed like they felt that their ID is a part of them:

‘but I say look, it’s part of me, if you don’t like it, I aren’t bothered ... its part of me and I’m not changing for you’ – Steven

ID was normalised by Steven; this appeared to contribute to his acceptance of his ID. He spoke about ID in the media and this seemed help him create understanding about his ID and identity:

‘have you ever seen the film ____? well she’s got autism, but she thinks of things in her head and puts it onto paper, that’s what I do, I’m a bit like that, I can create a story out of nowhere, or create a song or a poem and I’ll just write it down... or ... or I just write them down... that’s ‘cos of my autism’ – Steven.

There were emotional consequences to having an ID, in some cases these emotions were difficult to manage. Participants reported feeling frustrated, alone, depressed,
anxious and panicked. Annoyance arose from the difficulties that were experienced, such as problems completing work at school and other people ‘getting to’ them:

‘I find it erm... hard to breathe sometimes, I find it hard to breathe sometimes, because when people are at you and erm, they’re constantly with you when you want the space’ – Ian.

It is possible that this quote is suggestive of feelings of anxiety that follow a loss of control. A perceived loss of control appears to be common throughout the interviews, therefore anxiety may be an emotional consequence of having an ID.

At times, feelings associated with ID were invalidated:

‘when I found out about my err... disability... I felt ... I felt ... out of it... I says to my mam... I’m not normal... I’m not like other people... she says you are... don’t be daft...I says I’m not! So I says all lot of... why do people take the mickey out of me?’ – Jody.

Due to this, Jody learnt that focusing on deficits caused emotional distress. It seems that she did not have the opportunity to discuss how she felt as a child and therefore is avoidant of these negative emotions in her adulthood. Again, this may be demonstrating a hidden sadness, but feeling like she need to ‘get on with it’ and not address painful emotions, which may be resulting in her lack of acknowledgement of how she really feels.

I am Different

Participants reported feeling as though they are different to others, which may have made them feel vulnerable. At times, this vulnerability was not only a fear, but was a real threat, as Charlotte reported being bullied physically and emotionally:
‘I did get bullied... this lass... She smacked me and she got suspended for it’ – Charlotte.

Others reported being called derogatory names because of their disability:

‘yes, like spastic, I don’t like that, or you can’t talk... or you walk funny or something like that’ – Steven.

Some were targeted in their own homes and community due to their ID. For example, Arthur reported being burgled and abused on the bus. This resulted in having to move out of his village to a new home.

Participants spoke about themselves as separate from other people. They felt that people with an ID and people without are in separate categories, demonstrating a ‘them and us’ frame of mind. Participants carried the belief that others have a negative view of them. Again, this may reflect self-fulfilling prophecies:

‘cos it’s hard and people they keep thinking oh no they can’t get a job, they just sit on their backside and can’t go like jobs...’ – Charlotte.

Some people felt ‘special’ and spoke about having roles that made them feel important:

‘Erm...this lady told my mum that she was going to have another baby... and... then she said to my mum... this baby... is special...’ – Rachel.

Attending 'special schools' may have reiterated the idea that they are different from others. For some, this was reflected in knowing that they needed extra help at school or finding it difficult to communicate with unfamiliar people. Others found receiving help frustrating at times, it seemed that other people liked to provide help, but at times this help was not useful or welcomed.
‘Cos what I found difficult was people saying, oh do you want help doing that, and with me I just found it frustrating’ – Charlotte.

ID was spoken about as though it was a taboo subject:

‘a lot of people don’t do things about disabilities, they think it’s a difficult problem talking about learning disabilities, they don’t like talking about disabilities’ – Jade.

Conversations with participants reflected the opinion that there was not enough knowledge about what disability is. It was believed that some people were putting all disabilities into the same category and assuming that they are all the same, it seemed important to one participant that people understand that all people with disabilities are different and to be aware of the uniqueness of people with ID. This idea that ID should be recognised may be reflective of the individual’s wanting to feel integrated more into society. It seems that they hope that eliminating the taboo that is disability they would be integrated, reducing the ‘them and us’ divide.

**Managing Life’s Difficulties**

This theme demonstrates how the reported difficulties are managed. There are two subthemes; ‘Coping’ focuses on coping mechanisms that people use, some report coping strategies that they find useful and some report struggling to find ways to cope; ‘support and relationships’ suggests that family and friends are important in supporting people through challenges.
Coping

All participants spoke about hobbies, some were common everyday hobbies, such as playing on game consoles, going to the gym, doing sports and watching TV. Many made use of skills such as creativity and art:

‘(Art is) Good, ‘cos, it’s good for me and it relaxes me and it helps me’ – Charlotte.

Some hobbies had a purpose, such as helping people to cope and helping to make day to day life easier:

‘(I put) Animal music on, say like... I like my meerkats and I like my dolphins... so, I put my dolphin music on... it’ll soothe me... it relaxes me’ – Rachel.

Using the music for relaxation may be highlighting the anxiety that comes with having an ID.

Having a routine seemed to be key for all participants in being able to cope, many planned their days to make things easier to manage:

‘I come here 4 days a week, Monday to Thursday, nine to four, err... do all sorts, I do drama on a Monday morning... film studies in the afternoon, Tuesday morning we do independent living skills, so how to cope on your own if you lived on your own and stuff like that, your independent skills... in the afternoon its projects, on the Wednesday we’ve got IT, I’m not in this afternoon, it would usually be music, Thursday it’s erm... I’m going to be next door to do newspaper, but I’ve decided to move out of there to do art and design because I like doing art and design with my work, and on a Thursday afternoon its err... films’ – Steven.

‘I go to gym, four days a week... on a Tuesday night I play pool, on a Tuesday night, and then I get a taxi home... ... I go to football matches once a month and I get
a ticket for one pound!... and I’ve got my tablets come every Thursday... I get my shopping on Tuesday and Wednesday’ – Arthur.

Other strategies included; talking to trusted people about difficulties; attending a day centre; keeping busy; and being able to manage own needs. Arguments and conflict with others was discussed by some participants, they had managed to find ways to cope with this, such as walking away from trouble.

Humour was also a significant coping strategy that came up in the study, friends and family were central to this:

‘When they come here and they tell jokes and they make, come out with silly things, I’m always the joker (here) ha and wind people up a bit ha’ – Charlotte.

‘My (family member), yeah, he’s the younger one. He’s the terror ha-ha, he doesn’t look it! He doesn’t look it!’ – Nathan.

Some used humour as a coping mechanism, but at times sadness became apparent behind the laughter:

‘Nah, make no changes or nothing, and my life, its err done ha-ha I just carry on ha-ha that’s what... I just carry on!’ – Nathan.

Throughout the interviews there was a sense of accepting the way things are, getting on with it, and ‘just grin and grind it’ – Nathan. Some people chose not to focus on things they had difficulties with, but aimed at focusing on achievements and things that they are good at. Therefore, not dwelling on difficulties that may be experienced in life and having a non-blaming attitude with their ID. Although it should be noted that this may be suggesting avoidance of difficult emotions. Experiences in life lead to Ian envisaging what the future could have been like, therefore feeling lucky in the way that life has turned out and not focusing on deficits but on positive aspects of life.
Acceptance and focusing on strengths whilst being aware of difficulties allowed people to have aspirations and goals that were realistic and consistent with their abilities. This may have enabled them to feel more positive as they were able to reach their own goals, which gave them a sense of achievement as they were not setting themselves up for failure.

Although there was a sense of being able to cope with daily challenges and having an ID, for some this was not the case. Some spoke about situations where they felt as though they would be unable to cope. Becky spoke about how she did not feel as though she had any coping mechanisms. When asked how she coped she replied:

‘Erm... keep inside me’ to which the researcher asked, ‘Keep inside you, what do you mean by that?’ ‘Not tell anyone how I feel’ – Becky.

Becky described this ‘bottling up’ as one of her disabilities.

**Support and Relationships**

Relationships were an important aspect of people’s lives, friendships and inclusion were important to help them to feel some normality in their lives:

‘Cos, you make friends and you feel a bit like, normal when you come here like anywhere else it’s not...’ – Charlotte.

Being with people with similar experiences seemed to be a ‘safe-space’ for individuals, a place where they can be themselves with people that they trust:

‘what I enjoy the most is coming here, learning, seeing my friends and erm feeling safe’ – Steven.
Some participants opportunity to be involved in activities such as team sports days where they get matching coloured t-shirts and medals. Friends were considered, in some cases, as extended family as Rachel explained that she called her two closest friends her brother and sister.

Although, this inclusion at the day centre where they are in a ‘safe space’ with people with ID’s may not be giving a realistic view of the world, where not everyone we spend time with are considered friends. Therefore, not demonstrating the realistic nature of relationships, for example the difference between colleagues and friends. As a result, this may segregate them from others even more.

Romantic relationships were spoken about by some of the participants Ian spoke about his girlfriend teaching him how to manage arguments with others. He explained:

‘I think she’s the best girlfriend I’ve ever had...’ – Ian.

Although Ian spoke about the importance of his girlfriend, in most of the interviews romantic partners were not spoke about in a way that suggested that that they were the most significant relationships in people’s lives. More significant relationships mentioned were those of parents, family and friends. This appeared surprising as it would be thought that at the age of the participants, romantic relationships would become more important than parental relationships.

Parents played a significant role in almost all participant’s lives, parents took on a role providing practical and emotional support, such as taking care of medication and ensuring that they are taking care of themselves. There was less independence from the parents than would be expected as an individual becomes an adult. For example, Ian also explained:
‘mam and dad err... you’re very grateful to be having a mam and dad as err... your relationship is, will always be there, forever until err... but with like, my girlfriend it’s a different relationship because, yeah having your family is more important because they’re with you all the time, when you need them, but with your partner it’s erm like, you can’t be with them forever if it doesn’t work out’ – Ian.

It seems that this is not demonstrating a realistic outlook on life as parents are not there forever, and may pose further challenges in Ian’s life in the future when his parents are no longer around to support him, highlighting the importance of gaining independence in life.

Other family members were also important, Jody spoke about a member of the family that she was proud of:

‘I have a good relationship with (family member) ... he plays hockey, and he goes fishing ha-ha. Yeah... he gets a fish... and then he shows people on his mobile phone!’ – Jody.

Gaining support was important to all participants, friends were a source of support, in terms of emotional support and being someone to listen when feeling low. This support with friends seemed to be mutual. Support from carers, supporters and keyworkers, was also important. This included practical support such as sorting DIY and daily living skills, such as teaching people to cook meals.

The type of support that was offered was important, if the individual asked for the specific help that was needed the support was valuable. On the other hand, if the support was given without consideration of whether they needed it or not, it would become frustrating to them and they would find it unhelpful:
‘I don’t really find anything difficult in the day ‘cos... because... I err... I always ask, I always ask if I find anything difficult’ – Steven.

Again, effective support was important as it could help people to thrive. Arthur explained that after moving to another service, he learnt how to cook, could look after his own flat and manage his medication which he had not been allowed to do in the past.

**Approaches to Life**

The final theme is focused on the ways that people approach their lives. Two sub-themes are; ‘Growth’ which demonstrates that people develop a sense of achievement and building confidence using their own persistence and effort; and ‘Positivity’, despite the challenges, they all found positive things that helped them enjoy life.

**Growth**

All participants spoke about personal achievement which they had worked towards themselves. Most participants spoke about how attending classes such as Drama, IT and Independent Living Skills helped them to develop their skills. Many tried new things to help them learn new skills, which were taken forward in other aspects of their lives such as learning to cook, which helped with living independently.

Many attended college and some had been employed or worked voluntarily, which enabled them to develop skills, and gain recognition:

‘I’m proud of like, getting qualifications and getting certificates at the end of it, which I find very proud because it shows you like on what entry and what skills you’ve
gained on different projects you’ve done…. if I ever end up leaving here and I went for a job interview, it’s good to know what your qualities are and what you’re good at and what you’ve got the certificate for, and try and gain your into getting the job you want as long as you’ve got the right qualities for it…yeah, I find that getting them certificates, I’m finding that the qualities that are on it that I’ve done, I find that I’m very proud and good’ – Ian.

With persistence and effort, people were proactive in their self-development and made their own choices about what they wanted and what was important to them. Most participants were aware of their strengths and difficulties and this awareness enabled them to recognise what they needed to develop. Working towards their own projects and being able to say, ‘I did this’ was important to people.

Confidence was reflected in proving others wrong, as in some cases people did not believe that individuals were able to do certain things, and as a result restricted them. By being proactive and having goals, they could achieve what they wanted:

‘My mam, right, who I lived with, my mam said you wouldn’t live on your own! So, I’ve proved them wrong haven’t I! Yeah! my mam said… my mam said you wouldn’t have done it, and people said you wouldn’t do it Arthur, not on your own!!’ – Arthur.

Teaching voluntarily enabled one participant to develop confidence and have a voice:

‘Erm…err… when I started teaching err… they gave me quite a buzz, just seeing the look on the faces when they meet me… ‘cos they’re there just listening to me, and I feel proud when I do that’ – Becky.

A key factor in all interviews was gaining independence and taking control in their lives:
I’ve lived with my mam and I’ve never cooked lasagne or something like that before and err... anyways.... the reason it’s been good is because I can learn to cook meals for myself, out the freezer and I can have them whenever and it’s been good because I used to have microwave meals all the time, so it’s good for me to learn to have a proper meal’ – Steven.

This demonstrates how the moving away from home has enabled Steven to gain his independence and determination to learn.

Participants identified with having a role in their life, some were responsible for helping their parents with everyday tasks such as housework and shopping. For others helping other people was important such as helping other attendees at the day centre:

‘I get my work finished first, then if (name) or some of the other learners have a problem in doing things with theirs... then I will help them if they need it... and if (name) needs some help this afternoon then... I help doing the... doing the err... doing the music and stuff, so like I err... I like to... I like to help everybody really’ – Jade.

A few participants seemed as though they had been restricted by their roles and responsibilities. Jody spoke about how going out and going on cruises is not very possible for her as her mother is elderly and unable to go out. Nathan, who was the carer for two family members found that he had not had time for himself and as he was older, felt as though it was not possible to change this:

‘looking after (family member’s) all my life so... apart from when I was... oohh... 14... I was at work as well as looking after them, that was a feat in itself... Nah, make no changes or nothing, and my life, its err done ha-ha I just carry on ha-ha that’s what... I just carry on!’ – Nathan.
Although, a lot of participants had a supportive role for parents, at times this role was reversed, if people needed help they turned to their parents.

Ian spoke about his employment, he spoke about lots of different job roles that he had previously had, such as working in a sweet factory, watering the plants in greenhouses and looking after trolleys in a shop. He was proud of these roles that he had been in and gave him a sense of achievement. Voluntary roles were also important, Becky taught nurses specialising in ID about her ID and this made her feel special and listened to, which is something that she struggles with in her day to day life.

Participants seemed to create meaning in their lives for something positive that makes life worth living. Many participants could not think of aspects of their lives that they did not enjoy. This suggested that it was possible for individuals to find enjoyment in everything they do in life and again, not focus on the negative aspects of life.

Feeling included related to creating meaning in life, being a part of something and being heard was meaningful for some people. For others family gave life meaning:

‘It’s important to me that, just keep him occupied and happy. What life’s about, isn’t it really ha-ha? If he wasn’t here, I wouldn’t have been here, no, he kept me going, ha, kept me going he has’ – Nathan.

Positivity

People did not always focus on deficits and found positivity in their lives. Positivity did come of out having ID, as Steven suggested that it made them more creative:

‘that’s what I do, I’m a bit like that, I can create a story out of nowhere or create a song or a poem and I’ll just write it down… that’s cos of my autism’ – Steven.
Creative skills such as arts and crafts were mentioned by all participants as something that they enjoyed, with Arthur being the only exception to this. Nathan spoke about his achievements in art and that he was asked to go and teach art to children, which he turned down due to feeling as though it was too much for him due to his age.

Art was a strength that Nathan valued, valuing strengths was important as individuals could show that they had done something themselves and be proud of that. Showing people that they had achieved things themselves was important to them, by doing this they have demonstrated persistence and effort to achieve.

Others found positivity in strengths that they already had, using skills gained from employment and continuing this as a hobby, again this is demonstrating that people are not focused on deficits, but find value and enjoyment in what they are able to do.

Positivity was created by happiness in life:

‘Well, life, I enjoy life, that’s all I do, enjoy life.’ – Nathan.

Steven surprised himself by what they could achieve:

‘When I moved out, I used to hate change, but I adapted to change quite quickly! Cause usually with some people it takes a long time, but I actually adapted quite quickly’ – Steven.

This recognition of achievements helps in increasing self-esteem as they begin to have belief that they can do things and exceed their own expectations.

**Discussion**

The current study aimed to explore the experiences of people with ID and any challenges that they may face. Readers must be aware that due to this being a small-
scale IPA study, the interpretations are based on this sample alone and does not aim to generalise to the general population.

The challenges in life reported are consistent with previous research in that they felt different from their peers at times (Kenyon, Beail and Jackson 2013) and that some experienced bullying and name calling (Polloway, Shewel and Patto 1992; Connors and Stalker 2007; Starke 2011).

The majority of people did not appear to identify with ID when considering the criteria for a formal diagnosis of ID. People tended to discuss physical difficulties and everyday difficulties that could typically be experienced by anyone, regardless of having an ID. This is in line with research that people with ID do not appear to identify with the socially constructed label that is given to them (Beart, Hardy and Buchan 2005) e.g. the criteria for a formal diagnosis of ID. This could explain why in most cases, when asked ‘tell me about your ID’ people describe general difficulties that they have in life that would not be considered as ID. Some used common terms such as ‘mild learning disability’ which appeared to be diagnostic labels that were given to them, but they did not elaborate on what these mean, which seems to reflect them answering with the labels that they have been given without a real understanding or identifying to what that is.

Challenges played a significant role in people’s lives and motivated people to take a proactive role in their lives. This is consistent with the Dual-Systems Model (Wong 2012) and Second Wave Positive Psychology (Wong 2011) in demonstrating the importance of the dialectical nature of well-being. For example, in some cases they chose to move away from home and learn new skills even though they have challenges to overcome to do these things. The challenges that they faced motivated them to work
hard and achieve their goals. This resulted in them proving others wrong and having things to show for their work such as certificates and awards.

Again, in line with the Dual – Systems Model (Wong 2012) being proactive in situations did not always lead to a positive outcome. For example, one participant chose to move back home after finding independent living was too challenging. This outcome encouraged her to stay at home, which demonstrated acceptance of her abilities and taking an avoidant approach as moving out caused too much distress. This ‘avoidant’ approach was demonstrated in a few cases, whereby trying to be proactive and facing difficulties would cause too much distress. For example, avoiding difficult emotions and accepting ‘this is the way I am’.

It seems that the findings support the Social Model of Disability (Shakespeare 2013) as participants appear to manage well in life when they are enabled and provided opportunities. As a result, people find that they exceed the expectations of themselves and other people. This finding is important as service providers, supporters and families of people with ID can take this into consideration when providing support to individuals. In addition, there are difficulties that people with ID face. Therefore, asking individuals what they think they may need and allowing them to ask for help when they need it may enable them to reach their potential, thus reducing the impact of the difficulties encountered.

Parents played a significant role in almost all participant’s lives, this was interesting as it appeared that this relationship was different to what you would expect to see in a ‘typical life cycle’. For example, in Erikson’s (1950) Psychosocial Stages, it would be expected that people become more independent from parents in young adulthood and the parental role becomes much less significant and romantic relationships and independence take on a key role in people’s lives. Erikson suggests that avoiding these
intimate relationships can lead to loneliness and depression. This was different in the current study as it seemed like the parents still take on a very much parental role, and there was less independence from the parents than would be expected as an individual becomes an adult. The participants did not appear unhappy with this as Erikson suggested. Although, it could be argued that this ‘typical life cycle’ is a socially constructed idea.

Only three participants mentioned romantic partners but they did not mention these as their most significant relationships. Bates, Terry and Popple (2016) carried out research with adults with ID; they suggest that love is a basic need and being in a romantic relationship fulfils that need. Although some reported feeling lonely even if they have a partner, it was suggested that friendships meet this need, whereas romantic relationships provide affection and safety. This could provide an explanation as to why participants in the current study considered friends and parents as their most significant relationships as friends enabled inclusion and parents providing support for basic needs such as health and well-being. As these needs are being met by parents and friends, it could explain why there was no suggestion that they were lonely despite romantic partners not being a significant part of their lives. This contradicts Erikson’s (1950) suggestion that people would become lonely if they did not begin to build romantic relationships in young adulthood.

Finally, people were positive despite the challenges in ID, people found that they could achieve, grow and create meaning (eudemonic happiness) in their lives. Achievements, growth and meaning are aspects of positive psychology (Seligman and Csikszentmihalyi 2000). Hedonic happiness, is another aspect of well-being which is related to levels of positive affect being more focused on more that negative affect (Seligman and Csikszentmihalyi 2000). Participants could find this positivity by
recognising that there can be difficult aspects to life, but by focusing on the positive aspects as in hedonic happiness. Positivity came from determination and resulted in increased confidence and self-esteem. This is consistent in the theories behind Acceptance and Commitment Therapy (ACT, Harris [2007]) in that to create happiness in life, we must find acceptance in the pain that inevitably comes with life, and commit to working towards meaningful and valued activities. It appears most of the participants in the study work towards their values and thereby create meaning and enjoyment, whilst being aware of the difficulties that they face in life.

Relationships and a sense of community enabled participants to manage challenges in life, which the Positive Psychology Center (1998; cited in Hefferon and Boniwell, 2011) suggested was one factor in happiness. Individuals valued helping others and friendships their lives. In addition to this, creating positive individual attributes such as creativity was a factor in creating happiness (Positive Psychology Center, 1998; cited in Hefferon and Boniwell 2011). Creativity appeared to be important to people as it was a strength that they focused on which brought them a sense of achievement.

*Strengths and Limitations*

The present study had some strengths, for example the study focused on the experiences of individuals themselves. This allows for first-hand experience, which reduces any bias that may arise when interviewing family members or supporters. There was also a wide age range, allowing for an understanding of challenges at various stages of the adult life, which suggests that there are individuals differences in what is considered important in different life stages.

Although, the study was not without its limitations. Firstly, out of the nine participants seven were recruited from the same day centre. Many had similar everyday experiences and therefore may not have provided an accurate picture of the range of
experiences and the uniqueness of these. As a result, the study is in danger of putting people with ID in the same category, which was not the aim of the study. Therefore, it is accepted that the findings of the study may not be a true representation of the experiences of the larger population of people with ID. Although, a small-scale IPA study is not designed to be representative, therefore it is not the aim of the study to generalise to the general population.

A second limitation is that the questions were developed using the Dual-Systems Model. As a result of this, the categories of questions were around specific areas which then may have developed into themes. As a result, the themes may have been predetermined inadvertently prior to the analysis. Also, in terms of analysis, it may have been helpful for the researcher to have kept a reflective diary to follow how the thinking developed around themes, theories and ideas throughout the research.

Further Research

The current study examined the day to day lives of people with ID, there is surprisingly little research on this area. Further research could extend this knowledge by widening the range of participants. For example, research could examine cultural perspectives and expanding recruitment further than day service. This could enable the findings to be generalisable and allow for a more reliable understanding of what may be important in the lives of people with ID.

Secondly, it would be useful to gain understanding from the perspective of people without ID of what their thoughts are on ID and contrast this with actual experiences. This may help to remove stigma and negative attitudes, and as a result addressing the taboo that is disability.
Conclusions

Research in this area could be beneficial to services, professionals, families and the individuals themselves. The research considers any challenges that they may face in their lives, individual factors and cultural/contextual variables. This could be beneficial as the individuals have described approaches that have been the most effective to reach their optimal potential. Results from this study could also help services, carers and families understand how to provide support that is needed and most beneficial to the individual. This would enable individuals with ID optimal experiences and opportunities in life and see beyond the ID.

People with ID face challenges in their lives that may typically be faced in normal everyday life. At times, having an ID may pose challenges and exacerbate everyday difficulties or vice versa, but due to experience and being proactive people find ways to manage these, which most of the time are effective for them. This included adapting to situations and avoiding situations that increased vulnerability, at times they were limited by other people’s constructions of ID, as they would sometimes find themselves to be targeted or abused in certain contexts.

The participants in this study found positivity in ID by accepting life and not dwelling on the difficulties of life, but also being aware of their limitations to set realistic goals and strive towards living a value-led life. Relationships were a key part of being able to do this, particularly those of parents and friends.
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Appendix B: DMS V Autism Spectrum Disorder Guidelines

**Autism Spectrum Disorder**  
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**Diagnostic Criteria**

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

**Severity is based on social communication impairments and restricted repetitive patterns of behaviour** (see Table 2).

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyperreactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behaviour** (see Table 2).
C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:
With or without accompanying intellectual impairment
With or without accompanying language impairment
Associated with a known medical or genetic condition or environmental factor
(Coding note: Use additional code to identify the associated medical or genetic condition.)
Associated with another neurodevelopmental, mental, or behavioural disorder
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioural disorder[s].)
With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2  Severity levels for autism spectrum disorder

<table>
<thead>
<tr>
<th>Severity level</th>
<th>Social communication</th>
<th>Restricted, repetitive behaviours</th>
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<tbody>
<tr>
<td>Level 3</td>
<td>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches</td>
<td>Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.</td>
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<td>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even</td>
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<td>&quot;Requiring substantial support&quot;</td>
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with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Level 1
"Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
## Appendix C: Quality Checklist

**Study identification:** Include author, title, reference, year of publication

Gillian MacIntyre

The potential for inclusion: young people with learning disabilities experiences of social inclusion as they make the transition from childhood to adulthood

**Checklist completed by:** Gemma Whitney

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<td>is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?</td>
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<td>How systematic is the analysis, is the procedure reliable/dependable?</td>
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<td>Is it clear how the themes and concepts were derived from the data?</td>
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<td>Is the data 'rich'?</td>
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| | | For example:
| How well are the contexts of the data described? |
| Has the diversity of perspective and content been explored? |
| How well has the detail and depth been demonstrated? |
| Are responses compared and contrasted across groups/sites? |

### Reliability

| Is the analysis reliable? |
| For example: |
| Did more than 1 researcher theme and code transcripts/data? |
| If so, how were differences resolved? |
| Did participants feed back on the transcripts/data if possible and relevant? |
| Were negative/discrepant results addressed or ignored? |

### Results

| Participants | 9 |
| (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in |
the study, completing follow-up, and analysed

(b) Give reasons for non-participation at each stage

(c) Consider use of a flow diagram

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<td>Summarise key results with reference to study objectives</td>
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<td>Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias</td>
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<td>Give a cautious overall interpretation</td>
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of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence

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| Overall Assessment |    |                     |
### Appendix D: Quality Ratings

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<th>Methodological quality (assessed by checklist)</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Theoretical model specified</th>
</tr>
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<tbody>
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</table>

<table>
<thead>
<tr>
<th>Intervention used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td>Outcomes</td>
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<tr>
<td>Conclusions</td>
</tr>
<tr>
<td>Main Findings</td>
</tr>
</tbody>
</table>
Appendix F: Government Initiatives

Government initiatives have aimed to improve the lives of people with ID and ensure that they are driven by the views of people with ID and their carers (Department of Health 2010). The Valuing People Now (Department of Health 2010) strategy was a three-year plan which aimed to improve the lives of people with ID by providing them the same opportunities as a person without ID. Unacceptable treatment of people with ID and autism at Winterbourne View (Department of Health 2012) drove policies to be implemented in a more timely and effective manner. ‘Winterbourne View – Time for Change’ (Transforming Care and Commissioning Steering Group 2014) aimed to do this by calling for closure of institutions and introducing preventative measures i.e. better support in the community.

The Transforming Care Agenda (NHS England 2015) is a recent policy which is having a significant impact on health professionals working with people with ID. Their aims are to empower people with ID and their families, allowing them choice and ensuring that they are aware of their rights; to provide person-centred care; to provide care in their own home or an alternative to hospital when appropriate, reducing the amount of time spent in hospital; for regular inspections of services to ensure that they are working towards standards set by the Quality Care Commission (CQC).
Appendix G: Second Wave Positive Psychology and A Dual-Systems Model

Positive Psychology and Second Wave Positive Psychology

Psychology traditionally focuses on researching deficits in mental health and how individuals strive to recover from this (Seligman and Csikszentmihalyi 2000). Positive psychology aims to change this focus from deficits to building positive qualities in individuals and groups (Seligman and Csikszentmihalyi 2000).

Hefferon and Boniwell (2011) explain that positive psychology focuses on three periods in time; the past, present and future. A positive life includes being optimistic about the future, content with the past, and happy in the flow of life in the present. It is suggested that well-being is a combination of factors which are, subjective positive experiences in the above periods of time, focusing on positive individual characteristics and being a positive part of a community (Positive Psychology Center, [1998] as quoted by Hefferon and Boniwell [2011]).

There are criticisms of Positive Psychology such as overlooking negative experiences and emotions which are important as they motivate for positive change, for example regret and frustration can build strength and resilience (Wong 2011). Overestimating positives can be unrealistic and can lead to overlooking risk which can be counterproductive in encouraging and nurturing positive strengths.

The aim of second wave positive psychology is to consider the dialectical nature of well-being. Wong (2012) proposed a Dual-Systems Model that is in line with this theory. The model merges the ideas from positive psychology, second wave positive psychology and an existential perspective (learning to live with the negative side of
human life, such as suffering and loneliness) and is consistent with the compensation and adaptation approaches (Bognar 2015).

The approach and avoidance systems work interdependently, for example the avoidance system will warn the approach system of possible risks. Each system is more prominent in different situations, but they are most effective when used together to enable the most effective outcomes. The Dual-System’s Model is a key model in acknowledging that positive conditions can lead to both positive and negative outcomes and vice versa (Wong 2012).

Flexibility is key choosing the most appropriate solution to provide the most optimal outcome, for example, a situation that is incontrollable may require an avoidant approach as trying to control the incontrollable may cause distress and lead to a negative outcome.
Appendix H: Ethics Letter

Removed for Hard binding.
Appendix I: Recruitment Poster

Hello, my name is Gemma Whitney.

I am doing some research.

I would like to understand what it is like to have an Intellectual Disability.

For more information, please speak to a member of staff.

Email me: g.whitney@2011.hull.ac.uk

Or call me on: 07913 799702

Thank you!
I would like to invite you to take part in a research study.

This information sheet tells you all about the research.

Before you decide to take part it is important for you to understand why this research is being done and what it will involve.

Please take time to read this information sheet. It will help you to understand what is involved and help you decide if you want to take part in the research.

---

**Information Sheet**

An information sheet tells you everything you need to know about the research.

Read this before you decide to take part.

---

**What is the research about?**

My name is Gemma Whitney.

I am studying to become a Clinical Psychologist at the University of Hull
I am doing some research to find out what it is like to have an Intellectual Disability (this is sometimes called a Learning Disability). I would like to talk to people who have an Intellectual Disability about their lives. I would like to find out

What makes people happy?

What is difficult for people with Intellectual Disabilities?

What people do in a day.

**Why is the research important?**

The research is important as it will help people to understand what it is like to have an Intellectual Disability.

It is important that we hear about this from people who have Intellectual Disabilities.

**If you agree to take part I will:**
Call you

and find a date and time for us to meet.

It is up to you where you want to meet me.

I can visit you at your home with your supporter

or at your service, we will talk to the staff to arrange a suitable place to meet. It is up to you if you want your supporter in the room whilst we talk.
We will have two meetings. When I first meet with you, you will be asked to sign a consent form. You will be asked to write your initials or tick the boxes on the consent form.

**Consent Form**

Something that you sign.

This lets us know that you understand the writing in this sheet.

And that you agree to take part in the research.

If you are not able to read or write. I will read the information sheet to you. I will record you giving consent at the start of the interview.

If you want to take part, we will arrange another meeting together.

I will ask you some questions.

This should take about an hour and a half.

You can take any breaks you need. If the meeting feels too long, we can stop and meet another time.
I will ask you about yourself.

For example, ‘Do you live on your own or with someone else?’

I will then ask you questions about your day.

Such as, ‘What do you enjoy doing in a day?’

‘What do you not like in your usual day?’

The meeting will be recorded. This is so I can remember everything that is said.

I will listen to the recording after the meeting. I will write down what is said. This is so I can see what everyone has said to me and bring it together.
Anything that you say to me when we meet will be kept private. Only my supervisors and I will know what was said.

I will write down what we said. If you talk about people or places they will not be written down.

Because I am a student at a University, I will have to show my supervisors what I have written. My supervisors work at Hull University and are helping me with my research.

At times I may need to tell someone what you have said. If I am worried that you or someone else may be hurt, I might need to tell your support worker. I will talk with you about this first. I have to make sure that you and other people are safe. If I think you need to talk to somebody in private, I will give you a list of people who might be able to help you.
Taking part may be hard

- The research will take up some of your time.
- Some of the questions may be difficult to answer.
- We may talk about difficult things.

For example, other research says that people with Intellectual Disabilities may:

- Experience bullying.
- Need extra support.
- Have felt as though they are different.

We may talk about things like these and this may be upsetting for you.

If this happens you can tell me.

I will help you if you feel upset.
Taking part can be good

- We hope the research can help people with Intellectual Disabilities.
- It will give you time to talk
- It can help people understand how to give the best help that they can
- It would hopefully help people to understand Intellectual Disabilities.

You don’t have to take part

It is up to you whether you take part in the research.

You can say no,

No one will mind.

I will not come to see you.

You don’t have to tell me why.

You might decide to take part and then change your mind later on. This is OK. You can stop taking part at any time.
What if there is a problem?

If you become upset we can stop the meeting. I will try to help and answer your questions. We will start the meeting again after a break if you feel ok to.

If you feel like you need to talk to someone I will give you a list of people you can talk to.

You can talk to your supporter.

You can talk to a member of staff.

The University of Hull is paying for the research. They are helping to make sure everything is done right.

What do to do now if you want to take part?

If you would like to take part in the research, or if you have any questions, please get in touch with me:

Contact Details

Gemma Whitney
Email address: g.whitney2011@hull.ac.uk
If you want to take part, please leave your contact details below.

You will be contacted by the researcher to arrange a meeting.

Name:
..............................................................................................................................
..............................................................................................................................

Address:
..............................................................................................................................
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..............................................................................................................................
..............................................................................................................................
..............................................................................................................................

Telephone Number:
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Mobile Phone Number:
..............................................................................................................................
..............................................................................................................................

Are there any times of the day that you prefer to be contacted?
..............................................................................................................................
..............................................................................................................................

Signature:..............................................................................................................................
Date:..............................................................................................................................

Thank you very much for your interest!
Appendix K: Interview Schedule

Interview Schedule

Research questions

- What is day to day life like for people with ID?
- What are the positive aspects in life for people with ID?
- What challenges does a person with an ID face in their day to day lives?
- How do people with ID approach day to day life, and what are the outcomes of these approaches?

Background

Could you tell me a bit about yourself?

- How old are you?
- Tell me about your ID?
- What did you do when you first found out you had an ID?
- What is important to you?
- Do you have any hobbies? If yes, please tell me a bit about this?
- Do you have a job/attend a course? If yes, please tell me a bit about this?
- Who do you live with?

Day to Day Life

Describe what a normal/usual day is like for you?

- What has made you want to do these things?
- Tell me who is important to you?
• Could you tell us more about your relationship with these people? For example, what you do together, how do you know that person, do you think they help you, do you help them?

**Positive aspects in life**

Please tell me about what makes you happy in life

• What do you enjoy most?
• Why do you enjoy these things most?
• Could you describe something that you are proud of?
• What makes you proud of this?
• What did you do to achieve this?
• Do you feel like this has been good or bad? (Approach and outcome question)
• Could you explain to me why you think this has been good/bad?

**Challenges in life**

Is there anything that you find difficult in your daily life?

• Is there anything that you don’t enjoy?
• Why don’t you enjoy this?
• Could you tell me about a when you found things difficult?
• Why was this was a difficult time for you?
• Could you tell me about something you find difficult in a day?

**Approaches and Outcomes**
• You have just described things that you don’t like/ find difficult in your life. What do you do when you find something difficult?
• What do you do to make these things easier?
• How does this make it easier?
• What happens when you do this? Is it good or bad?
• Could you give me an example of a time you tried to make something in your life different? For example, changed job, started a class. What did you do? What happened when you did it? Was it good/bad? Where you happy with what happened?

Closing questions

• Is there anything else you think I need to know today?
• Is there anything I haven’t asked that you thought I would ask?
• Do you have anything that you would like to ask me?
Appendix L: Consent Form

CONSENT FORM

Name of Participant_____________

Title of Project: Personal Experiences of Living with an Intellectual Disability

This is the consent form.

Please write your initials in the boxes to say you want to take part.

I have read and understand the Information sheet.

I would like to take part.

I understand that I don’t have to take part if I don’t want to.

I understand I can leave the research at any time

Researcher: Gemma Whitney

Signed:…………………………
Date:…………………………
Thank you for talking to me today.

We may have talked about things that make you sad.

You might want to talk to someone.

Here is a list of people that can help.

You can ask someone to help you contact these people.
If you have questions about the research, you can contact me:

Gemma Whitney
Email address: g.whitney2011@hull.ac.uk

You can also speak to:
Dr Lesley Glover
Email address: l.f.glover@hull.ac.uk
Contact telephone number: 01482 464117

Dr Nick Hutchinson
Email address: n.hutchinson@hull.ac.uk
Contact telephone number 01482 464093

You could speak to someone in your family.

A member of staff.

Your supporter.

Your Doctor.
Online support

Mencap: https://www.mencap.org.uk

Scope: http://www.scope.org.uk/

Telephone support

Mencap direct: 0808 808 1111

Scope: 0808 800 3333
## Appendix N: Worked Example of Analysis

<table>
<thead>
<tr>
<th>Initial notes</th>
<th>Transcript</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Use of ‘slow’ (language) but getting thing done</strong></td>
<td>Well, erm, I’m not very good at reading. Mhmm</td>
<td>Academic/reading</td>
</tr>
<tr>
<td><strong>Being able to do things for enjoyment</strong></td>
<td>Err, I’m err, a bit slow hah, but err I get things done ha-ha</td>
<td>I’m a bit slow Perseverance</td>
</tr>
<tr>
<td></td>
<td>What do you mean by slow?</td>
<td>Things take longer (time)</td>
</tr>
<tr>
<td></td>
<td>I’m err, a bit slow doing things, yeah…. I like my drawings and all that and whatever</td>
<td></td>
</tr>
<tr>
<td></td>
<td>They’re really good them</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ahh, Queen Mary that!</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is it? Yeah, it’s really good</td>
<td>In control of own life Not restricted Independence</td>
</tr>
<tr>
<td></td>
<td>Yeah, err…. And err, I’ve everything… err… I like…</td>
<td></td>
</tr>
<tr>
<td></td>
<td>like… I seem to like, do what I want when I wanna do it ha-ha</td>
<td></td>
</tr>
<tr>
<td></td>
<td>So you’re able to do that then?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I can do that yeah, yeah</td>
<td>Physical difficulties</td>
</tr>
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<td></td>
<td>Can you tell me anything else about your learning disability?</td>
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<tr>
<td></td>
<td>Well, I’m not very good at walking Mhmm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Err… I’ve got a walking frame out there And err walking stick … I just err can’t go 100 yards, and I’m just down on the deck ha-ha</td>
<td>Humour as a coping strategy.</td>
</tr>
<tr>
<td></td>
<td>Yeah</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ha-ha</td>
<td></td>
</tr>
<tr>
<td></td>
<td>So you fall…</td>
<td>Safe space</td>
</tr>
<tr>
<td></td>
<td>I’m alright round her cause there plenty of place to sit</td>
<td>Typical aging difficulties</td>
</tr>
<tr>
<td></td>
<td>Mmm, yeah</td>
<td></td>
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<tr>
<td>Feeling like can’t help family member anymore because of age.</td>
<td></td>
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<td>---------------------------------</td>
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<td></td>
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<tr>
<td>Having a purpose, being the carer around the house. Not being cared for.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting time away</td>
<td></td>
<td></td>
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<tr>
<td>And erm, that’s about all, I’ve got angina, heart problems, and I’ve done all my side in, yep... I’ve done all my side in and that’s what’s... with all my side and that. Since then, I’ve not been very good at all ha</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No, lot of health problems?</td>
<td></td>
<td></td>
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<tr>
<td>Yeah health problems, I know I’ve got ____ (family member) but I can’t help him very much these days.</td>
<td></td>
<td></td>
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<tr>
<td>I’m too old for that ha-ha I’m too old ha-ha</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mmm, is ____ your (family member) then?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yeah, I’m his carer, so err... I look after him</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yeah, yeah</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We go on holidays and that, take him on holiday and all that</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yeah</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Having a role/purpose. |
| Caring not cared for |
| Having time away/holidays. |
| Connection with significant others. |
Appendix O: Example of Emergent Themes

Abstraction leading to the development of a super-ordinate theme

<table>
<thead>
<tr>
<th>Themes</th>
<th>Page/line</th>
<th>Key words/phrases</th>
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</thead>
<tbody>
<tr>
<td><strong>Difficulties encountered</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maths, English and reading difficulties in relation to ID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life with ID is harder</td>
<td><strong>Page 1, line 6</strong></td>
<td>I can’t erm… do maths… cos its hard and I can’t read… a bit… and I thought I can tell myself I find it frustrating to… to… read or spell or anything…</td>
</tr>
<tr>
<td></td>
<td><strong>Page 8, line 5</strong></td>
<td>Because its numbers and you’ve got to like add it up and… you can get it wrong</td>
</tr>
<tr>
<td></td>
<td><strong>Page 8, line 14</strong></td>
<td>spelling, because when I can’t spell out it frustrates me</td>
</tr>
<tr>
<td></td>
<td><strong>Pages 1, line 12</strong></td>
<td>when I was younger I had the mumps and I had really bad</td>
</tr>
<tr>
<td></td>
<td><strong>Page 1 line 30</strong></td>
<td>when I knew it first… I did have help… with my balance</td>
</tr>
<tr>
<td></td>
<td><strong>Page 1, line 24</strong></td>
<td>It’s just… harder… because none of the people, they doesn’t know what its, its like</td>
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<tr>
<td></td>
<td><strong>Page 2, line 3</strong></td>
<td>I had to go to the specialist school to… to go to</td>
</tr>
<tr>
<td></td>
<td><strong>Page 2, line 18</strong></td>
<td>For me it’s important for me to help me with my reading and spelling and my maths, and for my reading sometimes I do get my words mixed up, and sometimes I can’t understand it a bit…</td>
</tr>
<tr>
<td><strong>Feeling separate from others</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vulnerability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>wanting to feel normal them and us</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no one understands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I’m not normal, I’m different</td>
<td></td>
<td></td>
</tr>
<tr>
<td>annoyance at others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>bullying and being picked on</td>
<td></td>
<td></td>
</tr>
<tr>
<td>people have a negative opinion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>about us (thought bias-mind reading)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Page 5, line 23</strong></td>
<td>I just don’t like crowded people If they push you or knock you over and stuff</td>
</tr>
<tr>
<td></td>
<td><strong>Page 5, line 12</strong></td>
<td>Cos, you make friends and you feel a bit like, normal when you come here like anywhere else it’s not</td>
</tr>
<tr>
<td></td>
<td><strong>Page 2, line 13</strong></td>
<td>And I did get picked on, they’d call me goofy, and really…</td>
</tr>
<tr>
<td>Page, line</td>
<td>Text</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>------</td>
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<tr>
<td>2, 17</td>
<td>I did get bullied... this lass. She smacked me and she got suspended for it because none of the people, they doesn’t know what it’s it’s like cos its hard and people they keep thinking oh no they can’t get a job, they just sit on their backside and can’t go like jobs.</td>
<td></td>
</tr>
<tr>
<td>1, 24</td>
<td></td>
<td></td>
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<tr>
<td>5, 13</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>overcoming the difficulties</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2, 25</td>
<td>Yeah it does and I find it easier when someone writes something down for me and I copy it... The fitness, because it like, keeps you motivated and it helps you exercise and helps you lose weight a bit...</td>
<td></td>
</tr>
<tr>
<td>3 line 24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4, 2</td>
<td>I come here cos, to learn cos, I don’t think I’d get a job, cos I feel like it’s hard for me to go get a job or... that’s the reason I come here... and If someone goes oh you can do that... cos it’s that much so well I like doing a bit of shopping cos, sometimes it helps you with money skills and stuff,</td>
<td></td>
</tr>
<tr>
<td>5 line, 19</td>
<td>shopping is like, you learn about things like, what price they are or... if you’re not buying too much</td>
<td></td>
</tr>
<tr>
<td>6 line 27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7, 12</td>
<td>I’m proud of it because, I’ve done it and no one else hasn’t by me doing that I show people or I take a photo, that I’ve done it and what they’re... went to college at college there</td>
<td></td>
</tr>
<tr>
<td>7 line 16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 line, 19</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Creating meaning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1, 25</td>
<td>To have it and if I had not have it, I can just do things... myself</td>
<td></td>
</tr>
<tr>
<td>Positive relationships</td>
<td>Page 3, line 1</td>
<td>Page 3, line 5</td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------</td>
<td>---------------</td>
</tr>
<tr>
<td>safe space</td>
<td></td>
<td></td>
</tr>
<tr>
<td>togetherness with friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>caring family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>supportive family and friends</td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Work/recreation</th>
<th>Page 3, line 15</th>
<th>Page 4, line 2</th>
<th>Page 4, line 23</th>
</tr>
</thead>
<tbody>
<tr>
<td>voluntary work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>hobbies and social vs employment</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>recreation/hobbies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>art/creativity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>assuming there are a lack of options/job prospects</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I go to the gym twice a week,</td>
<td></td>
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<tr>
<td>I don’t think I’d get a job, cos I feel like it’s hard for me to go get a job or… that’s the reason I come here…</td>
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<tr>
<td>In my normal day-to-day life, I do art, like it helps me relax and it helps me concentrate with my art work</td>
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<tr>
<td>Erm… I work… I volunteer at a charity shop</td>
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<tr>
<td>Well I go out and like play pool, well we’ll come her and like play like pool on the night, after we’ve been here, after ______ cos you do things after _______.</td>
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<thead>
<tr>
<th>Emotional consequences of ID</th>
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<tr>
<td>frustration, annoyance</td>
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<tr>
<th>Yeah… I give then advice… you know… if they need it</th>
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<tr>
<td>Mmm, ok, what about in your day to day general life, is there anything you don’t enjoy? Nothing, that’s it,</td>
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Appendix P: Epistemological Statement

Epistemological Statement

Epistemology is an area of philosophy which focuses on how knowledge is derived, it’s relations to truth and how truth and knowledge can be justified (Bradley, 2015). According to Bradley (2015) beliefs are not ‘black and white’, some beliefs are backed up with evidence and others are not. There are many epistemological stances that a researcher could take (Hefferon, & Boniwell, 2011). The methods, underlying ideas, relationships built with participants and communication with the audience will be influenced by epistemology (Carter & Little, 2007). This statement aims to uncover the epistemology that drives the current study.

Constructivism is an approach that considers knowledge as a product of the individual’s interpretations of their world. This knowledge can be derived from their historical background, culture and individual circumstances (Gillet, 1998). This suggests that knowledge is subjective and not built on solid foundations, therefore there will be individual perspectives in people’s beliefs and values.

In some instances, the constructionist view appears to fit with the underlying assumptions of the current thesis, as the Social Model of Disability (Shakespeare, 2013) suggest that society, values and opinions play a part in defining what disability is. Attitudes surrounding disability can have an impact on the treatment an individual with a disability receives from people in society. Thus, impacting the opportunities that are available to people with Intellectual Disabilities (ID).

In addition, it was important to the researcher that individuals themselves were interviewed in the current study. The reasons for this, is that the researcher felt that different opinions and views would arise if significant others were interviewed. Again,
this fits with the constructionist view, as it is suggesting that there is no real ‘truth’ to experiences, as it can differ when considering different points of view.

To gain an understanding of the experiences of the individuals themselves, Interpretive Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009) was used to analyse the data which was useful in gaining an understanding of individual’s views. IPA explores individual’s subjective lived experiences and social cognitions. It also focuses on how the participant creates meaning in their lives in terms of events that happen and their interactions with the environment (Biggerstaff & Thompson, 2008).

On the other hand, it could be argued that research around disability could take a positivist stance. Researchers that take a constructivist stance are likely to disregard positivist stances (Madill, Jordan & Shirley, 2000) as positivists suggest that there is truth in knowledge based on scientific evidence and logic (Comte, 1865). Bognar (2015, page 46) asks the question ‘is disability just mere difference?’. As Bognar (2015) states, some disability is so debilitating, that even if views of society can be altered, there will still be substantial effects on a person’s life.

Considering both perspectives, the researcher considers herself to be of neither of the two, but finds value in both stances. The reason for this is that the research suggests views of society can exacerbate the difficulties that people may face. For example, they may experience bullying and abuse (Polloway, Shewel & Patto, 1992; Connors & Stalker, 2007) which then causes them to have to take an avoidant approach in life. A result of changing the views of others would aim to allow for inclusion in society. This is in line with the constructivist approaches, as knowledge can be changed which and result in a different outlook on disability.

On the other hand, in taking a positivist stance it could be argued that there are criteria to be met to be diagnosed with an ID (DSM 5th ed.; American Psychiatric Association,
2013; *ICD-10*, World Health Organisation, 1992) suggesting that there is some concrete evidence for ID. The severity of the impact of these difficulties has on the individual can differ depending on the severity of the ID. Therefore, even with inclusion and opportunities, the individual still has barriers that they face. As a result, it could be argued that even if views of society changed, then it still would have an impact on the individual’s life. An alternative opinion could be that the diagnostic criteria is also socially constructed and being given the ‘label’ can increase stigma and have a negative impact on an individual’s life.

When designing the research, the researcher’s epistemological stance has an influence. In this case, the researcher was aware that coming partly from a constructivist stance, people’s experiences around ID will be different. Therefore, she began by asking the question ‘Tell me about your ID?’ as she was interested in the meaning ID has for each participant. Also, within IPA, the researcher’s epistemological stance would influence the way in which data is analysed. The researchers own opinions, attitudes and experiences would be intertwined into their interpretation of other’s experiences. As a result, it is not the aim of the researcher to generalise these results to the general population, as she is aware that there are many influences and different points of view, therefore had the research been carried out with a different researcher and participants the interpretation may have not been the same. On the other hand, with an awareness that experiences and meaning can differ, the researcher did not wish to be disrespectful to participants, as ID is based on diagnostic criteria and may be very real and meaningful for them. Therefore, she did not want to be of the opinion that disability is all socially constructed as disability can be debilitating and the researcher did not wish to disregard this in her research.
In conclusion, it is difficult to conclude whether disability is a social construct as it can cause difficulties that may not be changed by altering views of others. By taking a stance between constructivism and positivism, the researcher feels that it is important for society to understand ID and reduce stigma surrounding ID having an awareness of the uniqueness of individuals. It is important to understand that individuals can face challenges that a person with ID may not face, as disability may not be ‘mere difference’, having a diagnostic criterion for ID supports this to a certain extent. Therefore, it should be recognised that extra support may be needed to be provided to enable them to reach their own potential and have optimal experiences.
References


Appendix Q: Reflective Statement

Reflective Statement

Choosing the topic of my empirical research was a difficult task for me. From personal experience and the areas that I had volunteered in, I found that I had so many areas I was interested in. A few of these were, eating disorders; Obsessive Compulsive Disorder (OCD); anxiety; and stigma surrounding mental health. Due to having little knowledge in any area, as I was at the beginning of my training, it made it even more difficult to choose as I didn’t really feel like I knew what I was doing.

On the day of the research fair, I attended but I was feeling very overwhelmed. There were many areas to choose from, but again having little experience at the time, none of it felt like it fitted for me. Not long after I had time off due to illness. I found that this put me behind, as on my return I found myself working on other aspects of the course that research went to the back of my mind. I felt that with three years ahead of me I had plenty of time, but the three years flew by.

I then started my first placement within a Community Learning Disability Team. When I began this placement, I had so much anxiety as I had never worked with people with ID and I was very apprehensive about it due to my own misconceptions of ID. When I began to find my feet, I realised how much I enjoyed working within this service. I found that the clients I was working with had so much strength and positivity, I found it inspiring as I felt I’d learnt so much from them. Despite the challenges that came with having a ID they seemed so motivated to make something of their lives. They took part in cooking classes; sports; craft classes; maths and English. My own assumptions were quickly challenged and my views changed.
Before I started the Doctorate Training, I did some work researching Positive Psychology and Dementia, which came to my mind again when working with on my placement. I thought that it seemed so fitting with the people I was working with that despite adversity they remained so positive. Although this was the case, I didn’t want to disregard the challenges that people face and only focus on the positives. After much reading around positive psychology, I discovered second wave positive psychology. This seemed to fit with what I was interested in, both the positives and negatives of living with a learning disability. This made me think simply, ‘What is it like living with a ID?’. Considering the people I was working with at the time, it felt was very important to me that I understand this from the individuals point of view, to get a true account from them. I felt like this could be a research project that I could feel passionate about, and one that I may never have considered at the very beginning.

I found 5th year a very difficult time in the course. I found myself struggling to focus on the research as everything else felt like it took priority over that. At this point, I began getting supervision for my research from Dr Lesley Glover and Dr Nick Hutchinson. They helped me to develop my ideas and focusing on trying to get ethical approval. I found gaining ethical approval a challenge, and found myself getting frustrated at this point in my research as I was eager to start, but found that I had hurdles to overcome before I started. On reflection, I would have looked into doing more research with ID prior to starting this process and spoke to other trainees researching ID more to understand more about what was needed. If I did this, I may not have found as many hurdles to jump along the way.

At this time whilst awaiting ethical approval, I had found a service that was very interested in helping me with recruitment. This was very valuable when it came to the recruitment stage, as I was prepared for this whilst awaiting ethical approval and
planning other aspects of the research. In creating documents such as the information sheets and interview schedule, piloting the initial ideas was very valuable. Having someone with an ID reading through materials was useful and helped me develop my project as this individual had lots of knowledge and experience that I did not have. I found recruitment and interviewing to be an enjoyable part of the research. I met a lot of people with interesting stories, and learnt much about what is available in the local area to support people with ID.

In terms of my Systematic Literature Review (SLR), I found it took a lot of time going through articles to decide on a topic of research. Finally, after all the reading I had done around the challenges of living with an ID, it was clear that the transition period into adulthood was a significant time when challenges arise. As there was already research on this period, I found that employment was an important event in anyone’s life, and with the challenges that someone with a ID might face, it was clear that this would be an interesting topic to research. In hindsight, I would have begun thinking about this part of the research much earlier, as I had not done an SLR before, I did not realise the time and detail that needed to go into the SLR.

When it came to the analysis, for both the SLR and empirical research, it started to feel like the research was coming together. Even though due to time pressures it was a stressful period, I found supervision kept me motivated. I enjoyed reading through transcripts and learning about people’s lives. I found a lot of positivity in the stories but also a lot of emotion, and I felt like I was beginning to fulfil what I set about hoping to achieve. Interpretive Phenomenological Analysis (IPA) related well to what I wanted to put across in my research. I am aware that in using a model such as the Dual-Systems model, I may have inadvertently predetermined my themes in the data. For example, I was interested in positivity and ID, therefore my interview questions
were around positivity and how difficulties are managed. As a result, ‘Managing Life’s Difficulties’ arose as a theme. This could be reflecting the researchers influence in IPA, as my own views that ID has positivity was an area that I wanted to be within the results, therefore I created questions around this. In future research that I may carry out, I will aim to be more aware of my own position in the research, as this is something I only felt aware of on reflection.

I found qualitative research enjoyable and found that my ideas and interests fitted with qualitative methods that quantitative. From completing this research, in comparison to my undergraduate dissertation, I felt that qualitative research fits my interests as I am interested in learning about people’s stories.

I enjoyed writing up the project as I saw all the hard work from the past three years coming together on paper. It helped me reflect on my journey through the research. Throughout the research I have found that I was taking inspiration from the participants that I was working with and to keep going even when things become difficult. I also found it important to take care of myself, doing things that I enjoy and remember what I valued in life.