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A COMPARISON OF THE NATURE AND SEVERITY OF WORRIES HELD BY ADOLESCENTS

WITH AND WITHOUT INTELLECTUAL DISABILITIES AS THEY APPROACH THE TRANSITION

AWAY FROM SCHOOL

Major Research Project and Clinical Research Portfolio

Volume 1

(Volume 2 bound separately)

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Psychology (D.Clin.Psy)

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Acknowledgements

CHAPTER 1: SYSTEMATIC REVIEW

Parents' Perceptions At the Time of Their Offspring's Transition to Adulthood: A Systematic Review of the Qualitative Literature

Running title: Parents' perceptions at the time of transition

Keywords: parents, transition, intellectual disability, qualitative

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Abstract

Background: The transition into adulthood is an important time for young people with intellectual disabilities (IDs). Parents' expectations of transition and their involvement in the process have been found to play a key role in predicting the success of this life-phase. In order to gain a better understanding of their perspectives, this review systematically examined qualitative studies of parents' experiences.

Materials and methods: Articles published since the start of the millennium were searched for in electronic databases. Relevant journals and the reference lists of selected articles were also hand-searched. Two clusters of studies were identified for inclusion. Cluster one included four small interview-based studies and cluster two was made up of two larger survey-based studies. The studies were subjected to a quality assessment and then synthesised, in their clusters, using meta-ethnography.

Results: Five themes were identified from the interview-based studies: finding the balance, remaining an advocate, teaching adulthood, feeling like an outsider, and frustration at limited opportunities. A sixth theme – reflecting on the life cycle - was found in the survey-based studies. Overall, the results suggested that parents wanted to support their child in developing independence, but found that different internal and external barriers interfered with this process.

Conclusions: There needs to be further consideration as to how to remove these barriers in order to make the most of the value that parents can bring to the transition process.

The period of adolescence and early adulthood is renowned as a psychologically challenging time when self-identity is formed and independence is increased (Foley et al, 2012; Forte et al, 2011; Blacher, 2001). Many developmental tasks are completed during this period. For example, friends have to be made without the assistance of parents or teachers, sexuality is developed and academic goals must be reached (Jones, 2012; Blacher, 2001). It has been proposed that these years of an individual's life dictate the level of self-determination that they develop which, in turn, has been found to impact upon their success in employment, financial management and independent living (Wehmeyer and Palmer, 2003).

Young people with intellectual disabilities (IDs) face the same challenges associated with transition as their typically intellectually functioning peers. They too are enrolled in a secondary school where they are likely to be expected to take greater responsibility for their own academic learning and achievements. Their sexuality will develop and they may want to build peer and romantic relationships (Pownall et al, 2011). However, these tasks can be made more complicated when there is a lack of appropriate resources necessary to achieve educational goals or a lack of further education or employment opportunities to motivate and reward the individual's efforts to learn. It has been identified that poorer social networks and increased supervision can also limit the opportunity for individuals to develop their sexuality and build appropriate peer relationships (Pownall et al, 2011; May and Simpson, 2003; Ferguson and Ferguson, 1996).

Many young people look to their parents for support with negotiating this difficult time-period and family involvement has been found, on many occasions, to be the strongest predictor of a successful transition (Foley et al, 2012). This in itself comes with many challenges as parents may feel unable to offer this support. Families of young people with intellectual disabilities have spoken about the period of transition to adulthood as being "the second shock", reminiscent of when they first received the news that their child had a pervasive disability (Hanley-Maxwell et al, 1995). Families have reported that it was during their child's adolescence and transition-period that they fully

realised the 'forever-ness' of their caring role and the life-long sacrifices that they would need to make in order to allow their child to have a reasonable quality of life (Schneider et al, 2006). In addition to these emotional adjustments, transition marks a period when other important social changes are taking place, all of which may place additional strain and pose practical challenges for the family. For example, it may be a time when other children are moving away from home and grandparents become less active and unwell (Foley et al, 2012; Schneider et al, 2006).

Parents can also be challenged by their own fears of transition at this time. Research has demonstrated that parents often become more risk averse during the transition period (Foley et al, 2012; Pownall et al, 2011; Smyth and McConkey, 2003). Smyth and McConkey (2003) carried out qualitative interviews with young people with intellectual disabilities and separately with their parents. They identified clear differences in the future aspirations that young people had for themselves when compared with their parents. There was an overall indication that the young people expected to be more independent and autonomous than their parents expected them to be.

Many studies have indicated that it is this incongruence between the parent and the young person's expectations of independence that leads to conflict during the transition period (Mills et al, 2009; Winik et al, 1985; Zetlin and Turner, 1985). In Zetlin and Turner's (1985) ethnographic study it was identified that parent-child relations were challenged when the young person perceived that their parents were interfering with their lives or being restrictive. Using the same data, Winik et al (1985) proposed that there were three types of parent-child relationships – supportive, dependent and conflict-ridden. They theorised that the type of relationship was determined by the level of concordance between the young person's aspirations and the amount of autonomy and support that they were given to meet their goals. Support for these findings has been offered more recently in Mill et al's (2009) qualitative study into the experiences of young adults with intellectual disabilities as they tried to negotiate autonomy in their families. They identified that young people were

defiant, passive or proactive in their approach depending upon the congruence between their perceived and desired levels of autonomy and their parental support.

It is clear that the views and expectations that parents hold have an impact on their children as they approach and move through the transition period. Given the significance of this period in shaping the young person's identity, self-determination and emotional development, it is important to understand parents' views better. Such an understanding may allow for more suitable supports to be offered to parents, helping to ease their stress and allowing them to more able to support their child to achieve developmental tasks.

Over the last ten to fifteen years, there has been an increase in the attention given to understanding of the perspectives of parents at the time of transition. Much of the research has taken the form of qualitative studies that have aimed to gain an insight into the parents' experiences and to identify common themes between families. To date, a critical review of the quality of these studies and their findings has not been carried out. It is now accepted as being appropriate to carry out a systematic review of qualitative studies by identifying and drawing together central themes (Shaw, 2011; Dixon-Woods et al, 2001). This method has been used extensively in health-based research, with a small number of qualitative reviews in the field of intellectual disabilities (Ali et al, 2012; Werner, 2012). Carrying out a qualitative review of studies that have investigated parents' perceptions of their offspring across the stage of transition may offer a greater theoretical insight into this topic area. It could also help to identify supports that are more sensitive to the needs of the parents, thus benefitting the wider family unit.

Research Question

What does the qualitative research tell us about the experiences of parents as their children with mild to moderate intellectual disabilities progress through the transition to adulthood?

Search Strategy

A three step strategy was adopted in order to identify all papers that were relevant to the current review.

1. An electronic search of databases was carried out in order to identify relevant studies. The databases PsychInfo and Cinahl were searched via EBSCO Host. Embase and Medline were searched via OVID. Each search was limited to journal articles published in the English language since the year 2000. It has been recommended that, due to the iterative nature of qualitative research, literature searches should be broad and inclusive (Barbour and Barbour, 2003). As such, a thorough search strategy using free text was used. The following keyword terms were searched on the 27th March 2013:

   A. Learning ADJ disab* OR mental* ADJ (retard* OR disab* OR handicap* OR incapa* OR impair*) OR intellect* ADJ (disab* OR incapa* OR handicap* OR impair*)

   B. Adolescen* OR teen* OR child* OR school-age* OR transition* OR youth* OR young ADJ (person OR people OR adult)

   C. Parent* OR mother* OR father* OR carer* OR famil* OR guardian*

   D. Qualitative OR grounded theory OR interpretative phenomenological OR narrative OR thematic analysis OR social constructionis* OR experience* OR content analysis OR grounded OR interview* OR ethnograph*

   E. A AND B AND C AND D

Following the electronic search, the articles that were identified were subjected to a three stage review process in comparison with the inclusion/exclusion criteria outlined below. This process began by reviewing the titles and discarding those which clearly met the exclusion criteria, before

then reviewing the abstracts of the remaining papers, discarding inappropriate articles, and then reviewing the full papers. A flowchart of the search results can be found in Figure 1.

[Insert Figure 1 about here]

2. Contents pages of relevant journals were also hand-searched in order to identify any additional relevant papers. The journals that were included in the hand-search were: British Journal of Learning Disabilities; Journal of Intellectual Disability Research; Journal of Applied Research in Intellectual Disabilities; American Journal on Mental Retardation/ American Journal on Intellectual and Developmental Disabilities; Mental Retardation/ Intellectual and Developmental Disabilities.

3. Reference lists for each of the identified papers were also searched for relevant studies.

Inclusion and Exclusion Criteria

Studies were included if they:

- Were qualitative in nature or had a qualitative component to their design;

- Included participants who were parents or parental guardians of young people with mild to moderate intellectual disabilities and who were within the transition age range of 18 to 26. This period has previously been defined as marking transition because it encompasses the launching phase into young adulthood (Blacher, 2001). It is during this time that offspring take on adult responsibilities such as managing their own money and when they become more autonomous in making decisions about their own lives.

- Investigated parents'/parental guardians' experiences of transition;

- Included participants who lived in Western cultures;

- Were published since the start of the new millennium;

- Were published in a peer review journal in English.

Studies were excluded if they:

- Were either unpublished, a case study or a book chapter;

- Also investigated either the views of parents of offspring who did not have IDs or the views of siblings/other family members and it was not possible to extract the data belonging to the parents of young people with IDs;

- Solely explored parents' perceptions of external factors, such as their views of transition services.

Search Results

The six papers that were included in this systematic review are detailed in Table 1. The selected papers can be separated into two clusters.

The first cluster is made up of four studies that used small sample sizes and collected data through open-ended interviews in which parents were asked to describe their experiences of transition (Gillan and Coughlan, 2010; Docherty and Reid, 2009; Bianco et al, 2009; Cooney, 2002). Cooney (2002) also interviewed the offspring and professionals working with the family, but only data from parents were included in the current review. The Bianco et al study included parents whose offspring were between 24 and 27 years old. Whilst the inclusion criteria specified that participants would be between the ages of 18 and 26, a decision was made to include this study as only one of their participants fell outside the set criteria.

 The second cluster is made up of two papers that used larger survey-based methodologies and collected qualitative data using open-ended questionnaires (Davies and Beamish, 2009; Rapanaro et al, 2008). In the Davies and Beamish study, parents were asked 50 questions that were split into three sections: (i) demographic details; (ii) details of the transition programme; (iii) post-school

activities, life satisfaction and adjustment to transition. The current review focuses on the responses to the third section only, which were made up of Likert scale questions with a space for additional comments. The Rapanaro et al study asked parents to: (i) describe a stressful event or situation encountered when caring for their child during transition; (ii) describe the negative and positive

[Insert Table 1 about here]

outcomes of the events and (iii) describe the negative and positive outcomes more generally associated with the chronic demands and on-going everyday responsibilities of caring for a son or daughter during transition. Again, the current review focuses on only the results from the third section of the study.

Rating of Studies

Attempts have been made by the research community to identify a method by which the quality of qualitative research can be assessed (Shaw, 2011; Dixon-Woods et al, 2006; Walsh and Downe, 2006). Whilst there is a lack of consensus, a tool that was devised for health based research by Walsh and Downe (2006) has been effectively used to evaluate qualitative studies. It was adapted for the current investigation and is outlined in Table 2. Each paper was compared to the 29 essential criteria and the presence of the criteria was recorded onto a matrix, which can be found in Table 3. Due to the lack of precision around evaluating characteristics of qualitative research, it was decided that the criteria would be used to guide a discussion about the quality of each paper, rather than to rule out papers that may not have met a predetermined standard. All of the papers involved were reviewed in this way by a second independent reviewer and any discrepancies in ratings were resolved through discussion.

Results of Quality Review

All of the papers within this systematic review described their scope and purpose well. Each identified a clear theory-driven rationale for the research. Specific research aims and purposes were outlined by all of the studies.

[Insert Table 2 about here]

The method and design were detailed in each paper and were appropriate. With regard to sampling, all studies targeted parents who were known to have transition-aged children with intellectual disabilities by contacting either special education schools, relevant charities or social services. Bianco et al (2009) excluded parents who were not available within a 6-week time frame and so they may have unintentionally prohibited busier families from taking part. Both of the larger scale studies acknowledged their relatively low response rates (27% for Davies and Beamish, 2009; and 29% for Rapanaro et al, 2008) and discussed these in the limitations sections. Level of disability was not always clearly stated, with most of the studies instead opting for a description of educational attainment or adaptive functioning skills that was indicative of levels of mild to moderate disability.

Five of the papers selected a recognised qualitative analytical approach. Cooney (2002) did not use an identifiable approach, instead stating the use of 'qualitative methods' and so it is difficult to evaluate how appropriate this was. The remaining interview-based studies selected to use methods appropriate for analysing rich data collected from smaller sample sizes (Gillan and Coughlan, 2010; Docherty and Reid, 2009; Bianco et al, 2009). Davies and Beamish (2009) and Rapanaro et al (2008) both used content analysis, as is appropriate for large-scale analysis of qualitative data.

All papers explained the approach that had been used. Three studies used a second researcher to analyse the data in order to increase the validity of the findings (Gillan and Coughlan, 2010; Rapanaro et al, 2008; Bianco et al, 2002). Docherty and Reid (2009) did not ask a second researcher to analyse the data but they did request participants to review the interpretations that had been made in order to ensure that the findings represented their experiences. A particular strength of the Bianco et al (2002) study was that it asked both participants and a second researcher to review the interpretations. A weakness of the Davies and Beamish (2009) paper is that it used neither types of second review. None of the papers discussed the issue of data saturation or provided a rationale for ending recruitment.

[Insert Table 3 about here]

The context of the study was described in each paper. However, the context was not clearly taken into account in the interpretations by Gillan and Coughlan (2010) or Davies and Beamish (2009). There were no clear trails to show how researchers came to their interpretations in any of the studies. Participant quotes were used to support the findings in all of the papers, with the exception of Gillan and Coughlan's (2010) study, where they instead stated the number of participants who shared each viewpoint. Researcher reflexivity was demonstrated in three of the papers (Bianco et al, 2009; Docherty and Reid, 2009; Cooney, 2002).

Ethical approval and documentation of how consent was gathered was specified in three of the papers (Gillan and Coughlan, 2010; Docherty and Reid, 2009; Rapanaro et al, 2008). Docherty and Reid (2009) also explained how they maintained confidentiality and anonymity.

Relevance and transferability were well described in all studies. Links were made to relevant theories and existing research. Limitations were detailed in each of the studies; however, this was restricted to a discussion of sample size in Cooney's (2002) paper. Directions for future research

were less well referenced with only three papers outlining ideas for further investigations (Gillan and Coughlan, 2010; Docherty and Reid, 2009; and Rapanaro et al, 2008).

Method of Synthesis

The method of meta-ethnography was selected to synthesise the findings of the different qualitative studies. Meta-ethnography is an acknowledged method for synthesising qualitative research in the topic of healthcare (Ring et al, 2011), thus making it most appropriate for this review. In addition, recent qualitative systematic reviews have demonstrated that meta-ethnography can be used to consider papers that have different qualitative methods alongside one another (Walter et al, 2004; Campbell et al, 2003), which proves useful for the present systematic review.

Meta-ethnography involves subsuming the concepts and themes that surround a particular topic, and which resonate with one another, into "higher order constructs" (Noblit and Hare, 1988). Noblit and Hare (1988) outline seven steps of meta-ethnography, each of which was carried out in the current review:

1.   Getting started – carrying out the search;

2.   Confirming initial interest;

3.   Reading studies and extracting data;

4.   Determining how studies are related;

5.   Translating studies;

6.   Synthesising translations;

7.   Expressing the synthesis.

The concept of "higher order constructs" has been described further since Noblit and Hare's (1988) seminal work (Shaw, 2011; Walter et al, 2004; Campbell et al, 2003). Through a process known as

reciprocal translation, first-order constructs (for example, the researchers' interpretations of parents' experiences) contained in each paper are examined and common themes, known as second-order constructs, are identified. These second-order constructs can then be interpreted further, to form third-order constructs, thus achieving a level of conceptual development beyond that which can be offered by the individual papers.

By breaking down the formation of "higher order constructs" into first, second and third-order constructs, researchers involved in conducting qualitative systematic reviews can leave an audit trail of their conclusions thus allowing the conclusions reached by their synthesis to be critically examined. This audit trail also facilitates easier replication of the review process.

Results

In the present review, the six papers identified as being appropriate for inclusion in the study were separated into two clusters due to their distinct differences in sample size, data collection methods and data analysis. They were synthesised separately in their clusters. At the outset of the review, it was not clear how well the two clusters of papers would map onto one another but it was felt that both types should be included given their relevance to the topic.

Second-Order Concepts

The clusters were separately subjected to a process of reciprocal translation. The mapping of the first-order constructs onto the second-order concepts for each of the two clusters is presented in Appendices 1.2 and 1.3. As demonstrated in Figure 2, synthesising the first cluster of interview-based studies identified the following five themes relating to parents' experiences of transition: (1) finding the balance, (2) remaining an advocate, (3) teaching adulthood, (4) feeling like an outsider, and (5) frustration at limited opportunities. Synthesising the second cluster also identified this fifth theme. In addition, it identified a new theme: (6) reflecting on the life cycle.

[Insert Figure 2 about here]

The content of each theme is described below. Participants' quotes are presented in italics.

1. *Finding the balance*

Parents in the studies reflected on the internal conflict they experienced in relation to supporting their child to become more independent. Docherty & Reid (2009) picked up the parents' need, not only to motivate their children to progress to adulthood, but also to motivate themselves towards that same goal, as expressed by this mother:

> *'Actually it would be a lot easier for me if he just stayed here. I wouldn't have the anxiety of him launching himself out'* (Docherty & Reid, 2009)

Some parents highlighted the vulnerabilities that they perceived their children to have – most commonly in managing their own money or in being assertive with other people. However, at the same time as stating that those vulnerabilities belonged to their child, they acknowledged that it was actually their own perceptions of the vulnerabilities that created a barrier to their children's independence as it stopped them from providing their child with opportunities to develop. In three of the studies, parents talked about the need to override their desire to be protective and spoke about how difficult and anxiety provoking it was to begin to allow their offspring to make their own decisions. One mother said:

> *'So I stepped back and thought, okay, Deb is agreeing to these activities. Let's see what happens…You're always rebalancing. Because you don't just stop from being the person who makes all the decisions. You're clumsy and graceless about it sometimes.'* (Bianco et al, 2009)

This quote highlights the mother's awareness that she is adjusting to a new role where she is required to observe decision-making rather than take an active part in it. Her use of the word

"always" when referring to rebalancing demonstrates a continuous process of adjustment during the transition phase and she acknowledges that she does not manage this with ease.

2. *Remaining an advocate*

Whilst trying to take steps back from being as involved in their child's life, parents in all studies emphasised that they had a vital on-going role as an advocate. One mother stated that she wanted her 25 year old daughter to have her own house because, at 25, she felt that this should be the case. However, the same mother also expressed the view:

> *'She's actually not in a position to make things happen for herself. That's my job. If she says that she has an interest in this or that then we go out of our way if it's feasible to make it happen.' (Docherty and Reid, 2009)*

There was a sense throughout the studies that, whilst parents were relinquishing some of their control, they would firmly ensure that their young person's views were heard. One father made use of transition meetings to express his daughter's interests and encourage others to build upon her strengths and successes:

> *'As I see it, it's important for us to build on her strengths. Working with people and continuing with her reading are things that will be important for her down the road. We should be approaching Carol's future using these as our lead. If we can find her a job at a nursing home, she'd be happy just to work where she's helping people. We want her to be doing the things she likes and that she's good at.' (Cooney, 2002)*

For the parents, being able to retain a key role in their young persons' lives, albeit from more of a distance than had previously been the case, appeared to be valued. In Gillan and Coughlan's (2010) study, parents stated that it was their on-going active involvement in their child's life that facilitated a successful transition.

3. Teaching adulthood

As well as taking on the role of advocate, parents also reflected that they had been required to attempt to teach their child about adulthood. For some, this involved teaching useful skills needed to live independently, for example, teaching how to use a mobile phone or how to manage money appropriately. For others, lessons that required to be taught were ones about the values and roles held in adulthood. Docherty and Reid (2009) expressed that it was in the introduction of values that parents believed their offspring would develop a concrete conceptualisation of adulthood. One example of this was from a mother who wanted to help her son understand that he was required to organise his own social activities rather than continue to accompany his parents where they went:

> *'So you have to be quite cruel, it's horrible, you have to say, Dad and I are going for a walk, what are you going to be doing?' (Docherty and Reid, 2009)*

This mother appears to have been trying to instil in her son the value of filling time and the need to be autonomous in doing so. Nonetheless, she feels she is being "cruel" in trying to evoke this common value of adulthood, perhaps demonstrating that her role as 'teacher of adulthood' is not a natural one. Another mother took a similar approach of trying to offer a concrete conceptualisation of adulthood by encouraging her son to self-advocate when going to a health appointment:

> *'When he did the sleep lab, I said, I'm leaving him. You'll have better communication with him without me there. Because if I'm there, he always turns to me and waits for me to answer the questions.' (Bianco et al, 2009)*

4. Feeling like an outsider

Feelings of frustration were reflected upon in discussions over the process of transition planning, in particular with regards to working with professionals. Cooney (2002) identified that parents felt alienated and inadequate at transition meetings attended by large groups of professionals. He summarised that some of these feelings were due to the uncertain outcomes, unfamiliar transition

terms and procedures, and unexpected barriers faced during the process. One parent, who was a teacher herself stated:

> *'I go to these meetings, and even being a teacher and knowing all the jargon, you are here and there are 13 other people on the other side of the table. Then, you think everything's going fine and all of a sudden they throw something in from left field. Like this is happening or that won't happen. And I'm thinking to myself "How am I going to deal with this?" It's like they speak in a foreign language.' (Cooney, 2002)*

This mother eloquently expresses the feeling of being an outsider. She is separated from the rest of the transition team in both her location at the other side of the table, in her lack of awareness of outcomes, and by the language that they share which she does not understand. This sense of isolation from others was also discussed by the parents in Gillan and Coughlan's (2010) study who expressed feelings of anxiety and frustration at dealing with "inflexible and unresponsive" services that felt unfamiliar and fragmented.

Parents in Bianco et al's (2009) study stated that they did not always feel that their relationships with agencies and service providers were welcomed or collaborative. They expressed the views that services did not appreciate the value of their contributions but that they still depended upon them to fill the gaps in support packages:

> *'Sometimes I feel as though in dealing with the different agencies, in dealing with people at BB [adult service agency] and DD [adult service agency] or even dealing with her own provider, that I am viewed as either being too lackadaisical about things or not really being as concerned as I should be, or just plain dumb…I just want to go up and shake people and say, "You know I carried this child in my body. I've been with her for all of this time and we've been through a lot and by golly I think I know how she is going to react to stations or how she's going to cope with this or you, please listen to me. I'm not just talking through my hat.' (Bianco et al, 2009)*

There is a sense of incredulity experienced by this mother as to why services would not take her opinion on board and why they would be so critical of her responses to her daughter. She expresses frustration at being considered a mere onlooker, side-lined when it comes to considering options or making decisions. She felt that she was not valued as the experienced mother that she considered herself to be.

5. *Frustration at limited opportunities*

A further common theme from the studies was that parents felt frustrated by the lack of opportunities. Parents expressed that limited opportunities prevented their young person from being able to demonstrate their skills and fulfil their potential:

> *'When I think of Paul at the workshop I think to myself, "What a waste, what a waste." Every time I hear about it I come home and stew to Frank [her husband]. It blows my mind to imagine that he could end up there. Nobody's doing anything there – all they do is sit around and sort screws. It's so frustrating to hear these things when I know Paul can do so much more'.*
> *(Cooney, 2002)*

The quote above is from a mother whose son was going through the transition process. During a transition meeting, it had been suggested to her that it would be "better" for her son to work in a sheltered workshop. Clearly to her, he would be disadvantaged, unable to achieve his potential and contribute positively. Social policy may have contributed to parents' frustration at the lack of opportunities. Within the United States of America, where Cooney's study was carried out, there is no federal family support system and families are expected to fund placements, at least in part, with only limited resources being provided by the government. The study was also conducted prior to the introduction of the Patient Protection and Affordable Care Act (2010) at a time when disabled people were significantly disadvantaged by the private healthcare system. Lack of government funded social care and private healthcare systems have also limited the opportunities offered at

transition to families in Ireland and Australia. In Gillan & Coughlan's (2010) study, carried out in Ireland, 10 parents highlighted the difficulties that they had experienced in terms of assisting their children to obtain and sustain jobs. In Davies and Beamish's (2009) larger survey-based Australian study, a parent made the following comment about the lack of employment opportunities available to them:

> *'He is stagnating and I can see him spending his life as a blimp in front of the computer or TV, from this point on there are very, very few employment opportunities these days for our special young adults. Very, very distressing!!' (Davies and Beamish, 2009)*

Where young people were not going to be working, parents were still keen that there should be a range of options for post-transition activities and they became frustrated when they felt their children were being inappropriately placed or where they had no activities at all:

> *'But then she graduated and they had no place for her. She was on a waiting list. And so she was at home with me for about 4 months.' (Bianco et al, 2009)*

There is a sense of powerlessness and helplessness in this parent's statement that was echoed throughout the studies as plans for post-transition activities were discussed.

6. *Reflecting on the life cycle*

An interesting theme that ran through both survey-based studies was one of parents craving a normal family life cycle and feeling negatively that their family had not progressed in the same way as families of typically developing young people. Rapanaro et al (2008) highlighted that the parents in their study sometimes felt resentful when observing the freedom of parents of children who did not have an intellectual disability. They described that this resentfulness led parents to reflect on previous experiences of loss and become aware that further loss is likely to happen in the future. One mother spoke about this experience in relation to giving up her job and losing her income when her child left school:

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'The family became emotionally dysfunctional and were unable to cope. Mother resigned from $60,000 per year job (and RESENTS it) to assist.' (Davies & Beamish, 2009).

There is a palpable sense of anger from this parent. Since Davies and Beamish (2009) carried out their study, there has been a review of government services for people with disabilities in Australia and a call for more equity of provision (Productivity Commission, 2011a, 2011b). Outcomes in Queensland, where this parent lived, were poor. For example, out of the 7 states in Australia, Queensland had the 4th highest rate of unemployment for people with disabilities (Productivity Commission, 2011b). It is acknowledged that shortages in day opportunities for people with IDs also impacts upon the employment opportunities for carers (Productivity Commission, 2011a). Similar feelings of anger and resentment were voiced by other parents in this study, which sometimes led on to expressions of guilt.

Parents' reflections on the family life cycle were also discussed in one of the interview-based projects. Docherty and Reid (2009) highlighted that parents felt entitled, due to their life-stage, to stop having continued responsibility for their children. Whilst all wanted ongoing involvement, they perceived that their responsibilities would be reduced after transition and anticipated a sense of relief:

'I'd feel more relaxed about doing things with Paul because then it's different. You're inviting them out as adults, as independent not as tagging along with you so it would be easier.' (Docherty & Reid, 2009)

This parent anticipates how they would feel if their son lived more independently – stating they would feel more relaxed as they would see their child as an adult. They express that this would be easier and, whilst it is not clear how this would be the case, there is a suggestion that this would be a sign of independence.

Discussion

The process of synthesising the findings of these studies has shed light on the experiences that parents of youth with mild to moderate intellectual disabilities have across their offspring's transition into adulthood. The studies included in this review indicate that parents recognise the need for their child to become more independent. They strive to achieve a balance whereby they can support their young person to develop autonomy whilst still managing the potential risks associated with adulthood. Parents take on roles as teachers and advocates to help facilitate these tasks. In supporting their child to move through transition they can experience barriers in the form of impenetrable transition processes and a lack of options for post-school activity. Parents experience these barriers with a sense of frustration. They may express similar emotions when they reflect on their past, current and future parenting roles and compare their own lives to those of their peers.

The parents in these studies recognised that their own fear could act as a barrier to their child moving on. This finding adds another dimension to previous research that found that parents became more risk averse during the transition period (Foley et al, 2012; Pownall et al, 2011; Smyth and McConkey, 2003). This review indicates that parents wish they could find it easier to relinquish control. As described, parent-child relations have been found to be mediated by the convergence between the parent's and the young person's expectations of independence at the time of transition (Mill et al, 2009; Winik et al, 1985; Zetlin and Turner, 1985). With this association in mind, it is encouraging that parents are making attempts to allow and support their child to have increased independence and it is important to consider how professionals can support this.

Parents also noted the differences in their own circumstances compared to those expected from a normal family life cycle. Typically, it is anticipated that the parent-child relationship will adjust during the child's adolescent years to allow the offspring to experience increased autonomy. By the time of transition, children are "launched" from the family home thereby allowing the parents to live as a

couple again and to develop adult-to-adult relationships with their children (Carter & McGoldrick, 1999). Some of the studies included in this review highlighted that the parents resented their loss of freedom and that they also felt guilty about that resentment. The emotions that parents expressed are in keeping with the research carried out by Hanley-Maxwell et al (1995) who found that transition provided an opportunity to reflect over past successes and challenges, whilst also preparing a vision for how the family's future would look. Earlier research proposed that in order to ease the adjustment, families need to grieve for their current and previous losses at transition points (Goldberg et al, 1995; Wikler et al, 1981). However, more recent research has promoted the role of acceptance-based interventions, such as mindfulness, to improve a family's ability to cope with changes and challenges. Often it is proposed that it is acceptance that mediates the family's adjustment and impacts upon their overall well-being (MacDonald et al, 2010; Hastings et al, 2006).

Family research indicates that there are not only roles for the parents in improving well-being at times of transition, but also with the individual with the disability and with the wider system (Blacher, 2001). Indeed, there are elements of the transition process that it would be unhelpful for parents to accept without question and it is their proactive involvement with systems and services makes a successful transition more likely (Knox et al, 2000). This systematic review excluded papers that focussed solely on parents' views or experiences of services. Yet, despite this, the impact that social care, education and employment services could have on the parent's overall perceptions of transition very clearly shines through. In particular, frustration at the limit of available options was raised in five of the six papers that were reviewed, taking into account views of parents who lived across three different countries. This provides an indication of how widespread the lack of opportunities is. Further research investigating the impact of the different policies that are applied by different countries would be beneficial in order to better understand which system-based elements can contribute to a successful transition.

This review has provided an opportunity to carefully consider the findings from two different types of qualitative data collection methods. A parallel was drawn between the expressions of parents in the two clusters with regards to the frustration experienced at the lack of options available. However, the larger survey-based research also unveiled the sense of resentment that parents felt at the time of transition. These expressions were absent from 3 of the 4 interview-based studies. It may be that parents found it easier to express negative emotion regarding the complexity of parenting a child with disabilities through indirect data-collection methods. In line with this, Docherty and Reid (2009), who carried out the only interview-based study where these emotions were discussed, detailed in their reflexive analysis that the researcher's mature age and her experience both as a mother and social care worker may have helped parents to feel that they could speak candidly without being judged. The effort to normalise these parents' feelings does not just apply to research but also to working with professionals.

Limitations

There are several limitations of the current review. None of the studies that were included detailed decisions made regarding data saturation. Satiation of data continues to be a contentious point within qualitative research and there is a lack of clarity over the number or length of interviews that will provide saturation (O'Reilly and Parker, 2013). However, if care had been taken to achieve saturation then it is possible that more themes may have been generated. More generally, the limitations regarding the quality of each of the individual studies impacts upon the current review. None of the papers provided an audit trail of their analysis and so it is not clear how their interpretations and themes were developed. As such, it is possible that a different person could go through this process and interpret the interviews differently. In some papers, it was also unclear whether the context was taken into account in the interpretations, which made it difficult to determine the meaning of some of the themes and views that emerged. For this reason, they were given less weight in the process of synthesising the data, with implications for the overarching

themes that emerged. For example, Gillan and Coughlan (2010) highlighted that parents found waiting lists to be a challenge, but as the context of this was not detailed, this finding was given less weight during the synthesis process.

With regards to the quality ratings, it is possible that the limitations placed on word counts by publishers of journals prohibited researchers from including certain details in their reports. This limits the value of conclusions drawn from the quality review. In addition, in order to achieve a level of quality, the search excluded book chapters and research dissertations, and so it is possible that some relevant data was missed. In connection with this point, Pope et al (2007) highlight that all systematic reviews of qualitative research face the weakness that qualitative literature is not well indexed in electronic databases, which are set-up primarily for quantitative studies.

Information about the socio-economic or employment status of parents was not consistently provided in the studies. Research has indicated a role for these factors in the perceptions and coping of parents and it would have been beneficial to discuss these features in the review (Raghavan et al, 2012; Emerson et al, 2003). There are also implications of the inclusion criteria applied to this review. Views of parents of youth with severe to profound IDs were not considered and it is possible that their experiences are qualitatively different to those parents who have offspring with mild to moderate IDs. In addition, the review only took into account the experiences of parents in Western countries: their experiences may be different to parents from the Eastern world. Furthermore, the review included studies with parents of sons and daughters who spanned a wide age-range in order to take account of experiences from across the transition period. A limitation of allowing such a broad age-range is that the differences in parents' experiences or perspectives at more discrete periods of time, such as when their sons or daughters first left school, may not have been fully represented. It would be of benefit to carry out qualitative research and further synthesis of findings with regard to more discrete periods of transition, as well as with parents of more severely disabled offspring and those from different countries.

Implications

This systematic review has provided an opportunity to consider the views of a large and varied group of parents across the phase of transition. The review has identified that parents can find transition challenging in both a practical and an emotional sense. Education, employment, health and social care services that are involved at this time should take into account the experiences of parents and consider how they can help to ease the challenges faced. In terms of practical challenges, services that are involved in transition could include parents as partners in the transition process and in doing so, they may be able to make use of the value that parents have as advocates and teachers, whilst also easing the frustration parents feel when excluded from meetings. It would also be useful if professionals could make time and be prepared to listen to the emotional experiences of parents who may be struggling to adjust to the changes that take place during transition.

<div align="center">

Conclusions

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In conclusion, parents of children with mild to moderate IDs play a key role in their offspring's transition into adulthood. Synthesising the findings of qualitative studies into parents' experiences of transition has indicated that they face a range of emotional and practical challenges. Professionals involved in the transition process should be prepared to listen to parents' concerns and consider ways that they can ease the challenges they face in order to make the most of the input that parents can offer during this important life phase.

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Table 1: Details of the studies selected for use in this review

Study	Scope of the paper	Country	Data Collection Method	Form of Analysis	Participants	Themes/ categories relevant to the review
Cooney (2002)	To examine the perspectives of young adults, parents and professionals in order to better understand how these perspectives influenced the overall quality of the transition experience.	America	Semi-structured interviews and observations at transition meetings	Non-specific qualitative research methods	Parents of 9 sons/daughters 5 males; 4 females Parent and offspring age ranges were not recorded.	(i) views of children; (ii) promise for the future; (iii) perspectives on transition.
Docherty and Reid (2009)	To understand the experience of mothers of young people with Down Syndrome during the transition period. Specifically to investigate the attitudes, values, goals and expectations underlying the experience. Also to understand the implications for the mothers of either continued dependency or a transition to independent living.	United Kingdom	Semi-structured interviews	Interpretative Phenomenological Analysis	Parents of 8 sons/daughters Gender ratio not recorded Parent age range 50-61 Offspring mean age 23	i) identifying stages of development - what is the next stage; (ii) defining and shaping adulthood: what are you going to be doing; (iii) gate-keeping and facilitating on the path to adulthood; (iv) self-reliance and independence as a value, goal and cultural norm.
Bianco et al (2009)	To solicit parents' voices to provide a better understanding of parents' experiences and perceptions of their roles during the post-high school years for their children with developmental disabilities.	America	Semi-structured interviews	Phenomenology	Parents of 9 sons/daughter 4 males; 5 females Parent age range not recorded Offspring age range 24-27	(i) parents as collaborators; (ii) parents as instructors, trainers, role models and mentors; (iii) parents as evaluators and decision makers; (iv) parents as system change agents.

Gillan and Coughlan (2010)	To understand the experiences of Irish parents at the time of transition. Specifically to focus on the impact of transition from high-support school environments to mainstream settings with potentially lower levels of formal supports.	Ireland	Semi-structured interviews	Grounded Theory	Parents of 8 sons/daughters Gender ratio not recorded Parent age range 42-65 Offspring age range 19-24	(i) meaning of transition for parents; (ii) psychological impact of transition experience; (iii) barriers and facilitators of the transition process; (iv) family system; (v) service system; (vi) wider social system.
Rapanaro et al (2008)	To explore and describe the negative and positive outcomes reported by parents in relation to: (a) particularly stressful events and (b) chronic caregiving demands encountered in the period of their son or daughter's transition into adulthood.	Australia	Questionnaires with open-ended questions	Content analysis	Parents of 119 sons/daughters 54% parents of sons Parent mean age 48.05 years (SD 5.82) Offspring age not recorded	(i) negative feelings/emotions; (ii) loss of freedom and independence; (iii) burnout; (iv) extra demands/pressure on resources; (v) negative impact on family; (vi) sense of fulfilment or pride; (vii) personal growth/enhanced personal resources; (viii) enhanced social network; (ix) absence of certain care demands;
Davies and Beamish (2009)	The study attempted to embed the fine grained ''life stories'' approach, more commonly used in small-scale research, within a large-scale investigation to better understand preparation for post school life and outcomes for the young adult and their family.	Australia	Questionnaires with open ended questions	Content analysis	Parents of 218 sons/daughters 60% parents of sons Parent age not recorded Offspring mode age 21	Impact on family adjustment relating to: (i) work; (ii) hours; (iii) care; (iv) lives; (v) week.

Table 2: Quality rating criteria (adapted from Walsh and Downe, 2006)

Stage	Essential Criteria Relating to Stage
Scope and purpose	Clear statement of focus and rationale for the research. The questions/aims/purpose are stated. Study thoroughly contextualised by existing literature.
Design	Method/design (i) apparent, (ii) consistent with research intent, and (ii) a rationale for it is given. The data collection strategy is apparent and appropriate.
Sampling strategy	The sample and sampling method (i) explained, (ii) justified and (iii) appropriate.
Analysis	The analytic approach is (i) explained and (ii) appropriate. More than one researcher involved if appropriate. There is participant involvement in the analysis. There is evidence of data saturation/discussion or rationale if not.
Interpretation	The context of the research is (i) described and (ii) taken account of in the interpretation. There is a clear audit trail (sufficient so that others can follow the decision trail) and data is used to support the interpretation.
Reflexivity	Researcher reflexivity demonstrated.
Ethical dimensions	Ethical approval granted. Documentation of how consent, confidentiality and anonymity were managed.
Relevance and transferability	There is an account of the study relevance and of the transferability of the evidence. Links are made to theories and literature. Limitations/weaknesses are outlined. Future directions for further research are outlined.

Table 3: Matrix of quality criteria arranged by study

Stage	Essential criteria	Bianco et al, 2009	Cooney, 2002	Gillan & Coughlan, 2010	Docherty & Reid, 2009	Davies & Beamish, 2009	Rapanaro et al, 2008
Scope and purpose	*Clear statement of focus for research*	X	X	X	X	X	X
	Rationale for research given	X	X	X	X	X	X
	Questions/ aims/purpose stated	X	X	X	X	X	X
	Study thoroughly contextualised by existing literature	X	X	X	X	X	X
Design	*Method/design apparent*	X	X	X	X	X	X
	Above consistent with research intent	X	X	X	X	X	X
	Rationale given	X	X	X	X	X	X
	Data collection strategy apparent	X	X	X	X	X	X
	Data collection strategy appropriate	X	X	X	X	X	X
Sampling strategy	*Sample and sampling method explained*	X	X	X	X	X	X
	Above justified	X	X	X	X	X	X
	Above appropriate	X	X	X	X	X	X
Analysis	*Analytic approach explained*	X	X	X	X	X	X
	Above appropriate	X	/	X	X	X	X
	More than one researcher involved if appropriate	X	/	X	/	/	X
	Participant involvement in analysis	X	/	/	X	/	/

	Evidence of data saturation/discussion or rationale if did not	/	/	/	/	/	/
Interpretation	*Context described*	X	X	X	X	X	X
	Context taken account of in interpretation	X	X	/	X	/	X
	Clear audit trail (sufficient so others can follow decision trail)	/	/	/	/	/	/
	Data used to support interpretation(i.e. direct quotes)	X	X	X	X	X	X
Reflexivity	*Researcher reflexivity demonstrated*	X	X	/	X	/	/
Ethical dimensions	*Ethical approval granted*	/	/	X	X	/	X
	Documentation of how consent was managed	/	/	X	X	/	X
	Documentation of how confidentiality and anonymity were managed	/	/	X	X	/	/
Relevance and transferability	*Relevance and transferability evidence*	X	X	X	X	X	X
	Links to theories and literature	X	X	X	X	X	X
	Limitations/weaknesses outlined	X	X	X	X	X	X
	Outlines further directions for research	/	/	X	X	/	X

'X' denotes the presence of the criteria; '/' denotes the absence of the criteria

Search of terms on EBSCO Host (PsychoInfo and Cinahl databases)

= 1892 articles identified

Search of terms on OVID (Embase and Medline databases)

= 1076 articles identified

After hand search to remove additional duplicates = 1715 articles identified

After hand search to remove additional duplicates = 1036 articles identified

After title search = 268 articles identified

After title search = 148 articles identified

Combined search after duplicates removed = 355 articles identified

After abstracts were reviewed = 45 articles identified

After full papers were reviewed, 39 were removed:

- 16 studies included participants with severe/profound disabilities or participants without intellectual disabilities.

- 10 studies had a focus out with the scope of this review

- 8 studies included participants out with the selected age-range

- 3 studies were either not qualitative or used group interviews

- 1 study took place in a non-Westernised country

- 1 study included non-relevant data that could not be separated from the relevant data.

6 studies identified as meeting the criteria for this review

After hand searching five relevant journals and reference lists = 0 additional articles identified

Figure 1: Flowchart depicting the search process and results
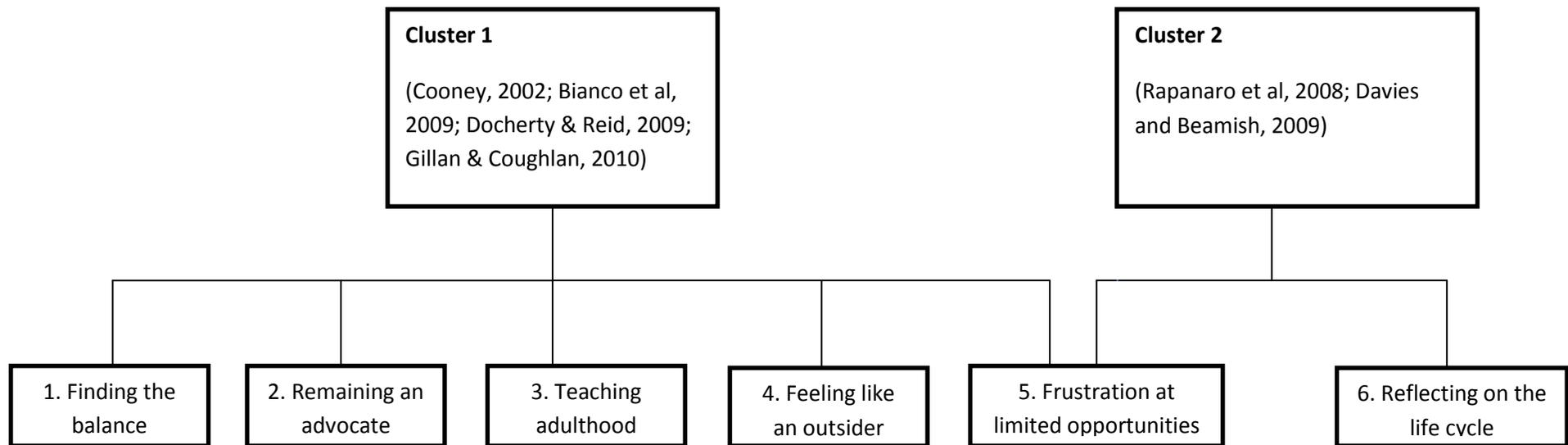
Figure 2: Flowchart depicting the second-order constructs that were formed after synthesising the findings of papers included within Cluster 1 and Cluster 2

A Comparison of the Nature and Severity of Worries Held by Adolescents With and Without

Intellectual Disabilities as They Approach the Transition Away From School

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Lay Summary

Background: The time when an adolescent is getting ready to leave school, a period which is known as transition, is particularly important. Previous research has shown that after transition young adults with intellectual disabilities (IDs) have different types of worries from adults without IDs and that these differences may represent variance in their life experiences (Forte et al, 2011). This research also found that the young adults with IDs ruminated more about their worries, that they were caused more distress by their worries and that they were more anxious overall. It was important to find out if this was also the case with younger people with IDs in order to inform whether supports should be put in place before they leave school that could contribute to improved mental well-being as adults.

Methods: Twenty-five participants with mild to moderate IDs and 27 participants without IDs, all aged 15 to 18, were recruited from schools in the West of Scotland. Participants were interviewed using an adapted version of the 'Worry Interview' that was used in Forte et al's (2011) study. This involved the participants looking at pictures that represented worry topics and deciding whether or not the topic was something they worried about. They also explained why they worried about the particular topic. The adolescents were asked about the following topics: school, further education, family, friendship, relationships, bullying, loneliness, work, money, home, appearance, health, decisions, failure and death. They also had an opportunity to say if they had particular worries that were not represented by these topics. Participants then identified their 4 biggest worries, and indicated how much they ruminated about each worry and how distressed each worry made them. Finally, their overall experience of anxiety was measured using a questionnaire called the Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID; Mindham and Espie, 2003).

Main Findings and Conclusions: The adolescents with IDs were more worried about death, relationships, bullying and making decisions than the adolescents without IDs, and they were less worried about failure, family, college and money. There were differences in the content of their

worries that might reflect experiences they have had that are linked to their disability. For example, the adolescents with IDs had fears of failure in many different areas of their lives whereas the adolescents without IDs mostly feared academic failure. They also worried more about current social threats, such as getting bullied. Unlike Forte et al's (2011) study, the ID group did not ruminate more about their worries, nor did their worries cause them more distress. However, they were much more anxious than the non-ID group. As expected, the adolescents who were more distressed by their worries were also more anxious. It is important that professionals working with young people with IDs enquire about their worries as they approach the end of school. This might allow the professional and adolescent to work together to identify the cause of their concern and possibly find a solution. Doing this might reduce the distress the adolescent experiences in association to the worry and might reduce their overall levels of anxiety. The Worry Interview could be used by professionals to open up conversations about worries with adolescents.

References

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Abstract

Background: The transition away from secondary school is an important time for adolescents, when identity is shaped and autonomy is increased. It is likely that this period can be particularly worrisome for people with intellectual disabilities (IDs) and it is possible that these worries will have an impact on mental well-being. This study sought to shed light on the content and implications of worries during the approach to transition.

Methods: Twenty-five participants with mild to moderate IDs and 27 participants without IDs, all aged 15 to 18, were recruited from schools in the West of Scotland. Participants were interviewed using a Worry Interview that had been adapted from previous research carried out with young adults with IDs. They also completed a measure of rumination and distress that related to their most salient worries. Anxiety was measured using the Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID).

Results: Content analysis of the interviews identified differences between the worries of the two groups of participants that may represent differences in life experiences. The distress that was linked to the worries was positively correlated with anxiety in both groups. The ID group were significantly more anxious than the non-ID group.

Conclusions: Consideration should be given to the specific worries of adolescents in the approach to transition. Doing so may allow solutions for their concerns to be identified, thus easing distress and leading to an overall impact on mental well-being. Limitations of the study and ideas for future research are discussed.

Borkovec et al (1983) define worry as consisting of a chain of repetitive verbal thoughts and images about possible future negative outcomes and about what the consequences of those outcomes could be. It has been suggested that the process of worry may be both protective and harmful. For example, it has been found to be positive in helping individuals to problem solve difficult situations, but worry is also thought to play a key role in the maintenance of anxiety disorders (Holaway et al, 2006; Szabo and Lovibond, 2002, 2004; Borkovec et al, 1998; Wells, 1997; Beck et al, 1985). These functions have significant implications. Mixed anxiety and depression accounts for the majority of mental health disorders that are treated in Britain, and their treatment places significant demand on health and social care. In addition, the ability to problem solve has been implicated in the process of developing resilience which, in turn, is related to successful outcomes in terms of daily functioning and mental well-being (Ager, 2013; Rutter, 2013; Werner, 1995). Given the significance of these implications it is not surprising that the evidence base surrounding worry has burgeoned in the last two decades.

However, despite the increased focus on worry in the general population, relatively little is known about worry amongst people with intellectual disabilities (IDs). Recent studies have indicated that mental health disorders, including anxiety disorders, are highly prevalent across the age-span in the ID population (Einfeld et al, 2011; Cooper et al, 2011, 2007; Emerson and Hatton, 2007). If worry is also implicated in the maintenance of anxiety disorders and in building resilience in people with ID, then it is important that the nature of their worries becomes better understood.

Age, life experience and societal factors have all been implicated in determining the content of worry. In non-disabled populations, there is evidence to suggest that even very young children worry (Muris et al, 2002; Vasey et al, 1994). However, the content of their worries changes over time. Worries that exist early in childhood have been found to be concrete and centred on physical safety, whereas by adolescence they are more abstract in nature and are more likely to be concerned with social-acceptance and psychological well-being (Cartwright-Hatton, 2006; Vasey et al, 1994). Vasey

et al (1994) linked this finding to the development of increasingly complex self-perceptions and an increasing awareness of social evaluation by others.

The limited research involving people with IDs provides some evidence to support the idea that the content of their worries is linked to their social experiences. Li and Morris (2007) found that older male adolescents with IDs had a higher level of fear associated with failure and criticism when compared to older females. They hypothesised that older males are exposed to more disparagement from their peers because of their disability and received less protection from adults because of their male status. Forte et al (2011) explored the worries of participants with and without IDs who were finishing their college courses and found that social experiences helped to shape the participants' concerns. Using a semi-structured 'Worry Interview', that was enhanced by the use of pictorial aids, they found significant differences in the content of the worries of their two participant groups that appeared to reflect differences in their previous experiences or current social circumstances. For example, the ID group's fear of death related to losing someone they were close to and a worry about how they could cope by themselves. In contrast, the non-ID group were concerned about their own mortality. Similarly, whilst very few people with IDs were being bullied at the time of the study, previous experience of bullying left them fearful that they would be bullied again in the future.

As previously mentioned, worries in themselves are not necessarily a sign of significant distress. It has been consistently found that it is the intensity of worry that differentiates non-pathological worry from pathological worry (Cartwright-Hatton, 2006). In Forte et al's (2011) study, participants rated the levels of rumination and distress that they experienced in relation to specific worries and also completed a measure of anxiety. It was found that the participants' distress and rumination scores were positively correlated with anxiety scores. At present, it is unclear why this link exists. A possible hypothesis suggested by Szabo and Lovibond (2004, 2002) is that pathological worriers are unable to problem-solve their worries and are distressed by the lack of resolution. Recent research about the link between meta-cognitive beliefs around worry (such as believing worry is dangerous)

may also explain why distress and pathological worry are linked (Cartwright-Hatton et al, 2004; Mather and Cartwright-Hatton, 2004; Wells, 1997, 1995). A further possibility, which is of particular relevance to people with IDs, is that increased distress may be linked to a reduced expectancy of success and a sense of helplessness. This has been highlighted as a common motivational feature in people with IDs and it can be associated with an increased likelihood of developing emotional disorders (Zigler et al, 2002; Zigler and Balla, 1982).

Forte et al's (2011) work with young adults who have left school points to the possible influence of their particular life experiences in not only the content of their worries, but also in the levels of rumination and distress associated with their worries. The research carried out by Forte et al is of particular value when considering the role and impact of worry due to its focus on a life transition. It is widely acknowledged that life transitions can threaten individuals' sense of well-being (Hulbert-Williams and Hastings, 2008) and so it is important to understand more about worry at these times.

A key life transition is the move away from school-based education. The transition from secondary school is renowned as a stressful time for all young people, including those with IDs (Foley et al, 2012; Forte et al, 2011; Blacher, 2001). This transition marks a time when identity is shaped and independence is increased. It is also a time when many developmental tasks are completed such as making friends without the assistance of teachers or parents and developing sexuality (Jones, 2012; Pownall et al, 2011). For people with IDs, these developmental tasks are already complicated. Their needs may increase at transition when they lose the support of a full-time education placement and they may experience uncertainty over whether or not they will get a job or college placement. The move away from school may also reduce adolescents' opportunities for social contact and limit their opportunities to maintain friendships or develop romantic relationships (McVilly et al, 2006). Due to a combination of the significance of this period and the rate of change that occurs within it, transition has been proposed to be a critical period in the development of resilience against mental health problems (Blacher, 2001).

The development of resilience is thought to be a process that occurs as a result of individual, family-based and systemic factors (Rutter, 2013; Werner, 1995). Educational programmes exist to enhance these factors through teaching self-care and interpersonal skills to children or adults who are at risk (Ager, 2013). For example, the Social and Emotional Aspects of Learning (SEAL) is a programme that has been developed in England and Wales with the aim of increasing young people's emotional resilience before they leave secondary school education (Department for Skills and Education, 2007). Community-based programmes also exist to support the development of resilience, for example, by educating residents about different cultures (Ager, 2013). However, these tools are aimed at supporting people who do not have an ID. It is unclear whether the content will address the particular experiences of adolescents with IDs and the specific worries that they have.

Forte et al's (2011) study highlights the concerns that young adults with IDs have prior to leaving college, it may be that the worries of adolescents, who have not yet left school and who have a different style of life, differ in content and severity. For the current study, it was thought that it would be helpful to replicate Forte et al's study with a younger group of adolescents who were still at school. This would allow the content of their worries to be examined and for the associated rumination and distress that they experience to be explored. In addition, it was thought that the findings could help to inform resilience building programmes to make them more applicable to adolescents with intellectual disabilities.

Research Questions and Hypotheses

The current study aimed to explore the content of the worry of adolescents with intellectual disabilities and their non-intellectually disabled peers in order to identify if there were differences between the groups. In addition, it was hypothesised that:

1. The ID group would have significantly higher levels of (a) rumination (b) distress and (c) anxiety than the non-ID group.

2. There would be positive correlations within both groups between the levels of distress, rumination and anxiety experienced by participants.

Method

Participants

Twenty-six young people with ID and twenty-nine young people without IDs were recruited from local authority schools in the West of Scotland. All participants were aged between 15 and 18. This age range was identified by the local healthcare service for children and adolescents with intellectual disabilities as being the age at which young people would be aware that they were approaching the end of school because they can choose to leave once they become 16 years old. All participants with IDs were recruited from special education schools and all had an IQ that fell within the mild to moderate learning disability range. After taking confidence intervals into account, this was defined as an estimated IQ that fell below 77 on the two-subtest Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). Participants in the non-ID group had an IQ that fell within the limits of average intelligence (an estimated IQ between 80 and 120). Participants were only included in the study if they were able to provide informed consent, were English speaking and had reasonable verbal communication. Reasonable verbal communication was determined by information from the participants' school teachers using the following components of the Adaptive Behaviour Scale (ABS-RC: 2; Nihira et al, 1993) as a guide: (a) talks to others about sports, family, group activities etc.; (b) sometimes uses complex sentences containing 'because', 'but' etc., and; (c) answers simple questions such as 'What is your name?' or 'What are you doing?' Participants were excluded if they had a degree of sensory impairment that meant they could not complete the task. Attempts were made to match groups as closely as possible with regard to age, gender and socio-economic status.

Following data collection, it was found that one participant recruited to the ID group had an estimated IQ that fell above 77 on the two-subtest WASI, suggesting that they did not have an ID. A

further participant recruited to the non-ID group had an estimated IQ above 120 suggesting their intelligence was outwith average limits. Data from both these participants were excluded from the analyses. Data from an additional participant was excluded as they had experience of both special and mainstream secondary school education.

Design

A between-subjects qualitative and quantitative design was used to explore the content of the worries and to identify any differences between the two groups in terms of the rumination and distress associated with their worries or between their overall levels of anxiety. A within-subject quantitative design was used to explore associations between rumination, distress and anxiety.

Measures and Interview

The measures and the worry interview are described below. They are presented in the order that they were administered to the participants.

1) A background information sheet was used to collect information on the participants' age, gender and socio-economic status. Socio-economic status was determined using the Carstairs Index (McLoone, 2004). This allows a person's status to be rated on a scale of 1-7 based upon their postcode, where 1 represents the most affluent postcode and 7 represents the most deprived.

2) The 'Worry Interview' was used to gather information on the participants' most salient worries and the extent of the distress and frequency of rumination caused by these worries. The Worry Interview was devised by Forte et al (2011) for a study investigating the worries of college-attendees. It uses a semi-structured format and pictorial representations of carefully identified 'worry topics' to establish a dialogue about the participants' worries. The worry topics covered the following areas: school, further education, family, friendship, relationships, bullying, loneliness, work, money, home, appearance, health, decisions, failure and death. These worry topics were selected after careful piloting, as described in the 'Pilot Study' section below.

Participants were shown a picture of a worry topic (such as a picture representing a work place) and asked, "what is this picture of?" and then, "what does this picture make you think of?" After the participants had been given the opportunity to talk about each of the photographs, they were asked to place the pictures on either a mat that had "yes" written on it and represented 'yes, this is a worry for me just now' or on a mat that had "no" written on it and represented 'no, this is not a worry for me just now'. Worry topics were presented in a randomised order across participant groups with the purpose of avoiding order effects. Once the participants had sorted all of the pictures between the two mats, they were asked if they had any worries that had not been discussed that could be added to the yes pile. The pictures in the 'no' pile were discarded and the participant was asked further questions regarding rumination and distress relating to the worries represented by the pictures in the 'yes' pile. For each photograph in the 'yes' pile, in order to provide a measure of their rumination and distress, participants were asked to rate on a 3-point visual analogue scale, "how often do you worry about this [sometimes, often, always]" and then, "how upset do you feel when you think about this [a little, quite a bit, a lot]". Prior to rating the worries for rumination and distress, time was spent with the participants to allow them the practise using the 3-point scale to rate frequency and magnitude in order to ensure they could use the tool correctly. Finally, the participants were shown a picture of 4 boxes, each of which gradually decreased in size from the box before it. After this picture was shown and discussed, participants were asked to pick their 4 biggest worries from their pile of worry topics and rank them in order of the biggest to the smallest. The resources used in the Worry Interview are shown in Appendix 2.2, 2.3 and 2.4.

3) The Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID) was used to measure the participants' levels of anxiety. This 27-item scale was developed by Mindham and Espie (2003) specifically for use with ID populations. Participants were encouraged to identify an anchor event that occurred 1 week previously and to answer the questions about worries, fears and physiological symptoms over the 7 days since the anchor event. For each of the 27

questions, participants could respond 'never', 'sometimes' or 'always'. Answers were scored a 0, 1 or 2 accordingly, allowing for a maximum final score of 54. The GAS-ID has good test-retest reliability (r=0.95), good internal consistency (alpha=0.96) and produces reasonable convergent validity correlations with the Beck Anxiety Inventory (rho=0.75). A copy of the GAS-ID can be found in Appendix 2.5.

4) The two subtest form of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) was used. The WASI links to the Wechsler Intelligence Scale for Children – 4th Edition (WISC-IV; Wechsler, 2003) in order to provide a measure of full scale intellectual functioning (FSIQ). In its two subtest form, the WASI consists of the tests 'Vocabulary' and 'Matrix Reasoning'. Psychometric properties of both subtests and the overall 2-subtest-FSIQ are reasonable. Convergent validity correlations between the WASI and WISC-IV are 0.79 for Vocabulary, 0.71 for Matrix Reasoning and 0.83 for the overall 2 subtest FSIQ. Test-retest reliability correlations are also good for children completing both the Vocabulary subtest (0.85) and the Matrix Reasoning subtest (0.77).

Procedure

To recruit participants, the researcher contacted head-teachers of local schools to request permission to carry out the research with their pupils. Teachers then identified groups of adolescents who met the participant criteria, gave them information sheets for the project and invited them, on behalf of the researcher, to take part. Pupils who wanted to take part completed a consent form and arranged a time to meet with the researcher via their teacher. Where participants were aged under 16 years of age, an appropriate adult offered consent and the participant gave their assent to participate.

The interview sessions took place in a private room within the participants' schools. Each session lasted approximately 40 minutes. Cognitive testing was undertaken last as it had right and wrong

answers and therefore clashed with the spirit of the Worry Interview and self-report measure, where it was desirable for participants to feel that they could express themselves openly without fear of making mistakes. When needed, in order to maintain the participants' engagement and attention, breaks were given. Participants were also given the option of splitting the session across two days. The Worry Interviews were audio recorded and transcribed verbatim.

Pilot Study

Prior to the main interview, a pilot of the Worry Interview was carried out with 2 adolescents with IDs who were not included in the main study. The purpose of this pilot was to identify whether any adaptations needed to be made to the interview from when it was used in Forte et al's (2011) study in order to make it more applicable to a younger population. Forte et al carefully selected their worry topics from a study conducted by Miller and Gallagher (1996) which investigated the worries of adolescents without IDs. Additional worries that can be experienced by younger children and adolescents, as identified by Silverman et al (1995), were also included in the pilot in order to explore whether it would be useful to incorporate them into the original Worry Interview. From the pilot, it was determined that the worry topics of appearance and health should be added. No other adaptations were required.

Justification of Sample Size

This was predominantly an exploratory study into the worries of pre-transition adolescents with IDs. However, as there was also a quantitative component relating to the distress, rumination and anxiety scores, a sample size calculation was carried out using data from Forte et al's (2011) study. These calculations indicated that, to achieve power of 0.8 at an alpha level of 0.05 for a one-tailed independent t-test, a sample size of 30 participants in each group would be required to identify a significant difference between the rumination scores. Based on the same power, it was calculated that a sample size of 8 participants per group would be required to identify a difference between the

distress scores of the two groups. It was decided that the study would opt to recruit to the more conservative of these two estimates.

Ethical Approval

Ethical approval was granted by the University of Glasgow College of Medical, Veterinary and Life Sciences (MVLS) Ethics Panel. A copy of the ethical approval letter can be found in Appendix 2.6. In addition, approval to carry out the research in schools was sought and granted from each Education Department of the Local Authorities involved in the study.

<div align="center">

Results

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Sample

Data from 25 adolescents with IDs and from 27 adolescents without IDs were used in the study. The demographic details for the two groups are shown in Table 1. There was a majority of females in the non-ID group and a majority of males in the ID group. However, the groups were well matched in terms of age and socio-economic status. The sample lived in areas of high deprivation split between inner-city locations and suburban towns situated near to the city. Seven adolescents in the ID group were cared for by foster carers whilst the rest of the participants lived with their own families.

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[Insert Table 1 about here]

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Worry Topics

Most salient worries

After sorting through the worry topics, participants selected their four "biggest" worries. The most salient worry topic was given a score of four, the second most salient was given a score of 3, and so on. Sums of scores for each topic were calculated for the two groups in order to identify the most salient worries per group. The results are shown in Figure 1 in decreasing order of salience according to the ID group.

There were notable discrepancies between the salience of particular worries for the two groups. The ID group were markedly more concerned about death, relationships, bullying and decisions than the non-ID group. In turn, the non-ID group were markedly more concerned about failure, family, college and money.

[Insert Figure 1 about here]

Content of Worries

Recordings of the Worry Interview were transcribed verbatim and then subjected to content analysis (Strauss, 1987). This process involved identifying the types of worry that emerged from the participants' transcripts in relation to each topic covered and then developing sets of categories that reflected the views expressed. An independent rater was asked to assign the participants' worries for each topic area into the categories that were developed. The independent rater assigned the participants' worries to the categories with 100% accuracy.

The most common worry for each of the topics is detailed by group in Table 2 below. Additional worry content identified by the content analysis can be found in Appendix 2.7 and 2.8. Content for the aforementioned worries, where there was a discrepancy in the salience between the two

groups, is described further below. Quotes of commonly occurring types of content are provided in italics.

Death.

Participants in the ID group who said they worried about death went on to speak about past experiences of bereavement and their continuing distress about these losses:

> *'Yeah 'cause my wee sister died a while ago, like my blood sister… last year I took flowers to her grave but I couldn't stop crying. I was crying for about 3 hours when I got home from it… I lost my granddad as well a few months after. He used to take me everywhere. He used to get me loads of sweets which I really loved.'* (Female from the ID group)

Participants in the non-ID group predominantly spoke about fearing their own deaths. Several mentioned that they were worried that they would not have the opportunity to have a full or happy life before their death:

> *'It's just that worry at this stage in your life when you're making major decisions that could change the course of your life - what if it does change for the worse. What if you don't do anything, what if you die without actually having had a happy life?'* (Female from the non-ID group)

Relationships.

There was a subtle but apparent difference in the worries of the two groups with regard to relationships. The ID group predominantly worried about not being able to get into a relationship:

> *'I don't get so far of "What will it be like", the only furthest I've ever got is "Would I ever get someone". It's worrying that I'll be all alone… it's pretty rubbish; I don't want to be alone. Something could happen to you and there would be no one there to help you. Somebody could*

break into your house and you wouldn't have a man there to help you.' (Female from the non-ID group)

The non-ID group were much less worried about relationships (it was their 11th most salient worry). Rather than being anxious about getting into a relationship, they feared that they would not find the person who was right for them:

'I always see my friends like and all that, most of them have girlfriends, but every time I do, it doesn't really last very long. Like, apparently I have commitment issues. I care too much. It really worries me, because I just wonder, will I ever manage to find the right person?' (Male from the non-ID group)

Bullying.

Bullying was the 7th biggest worry for the ID group. The majority of people who expressed worries about bullying spoke about experiences of being bullied at the moment:

'Some boys, some boys bully me from school. It's because I've got this kind of hair.' (Female from the ID group)

No one in the non-ID group mentioned that they were worried about being bullied at the moment. Instead, when they spoke about bullying, they worried about other friends or pupils getting bullied:

'It's not direct to me, but through someone else. Like if they're bullying someone it can affect me because I'm friends with this person and they call me crying and all that.' (Male from the non-ID group)

Decisions.

There were more similarities between the worries relating to making decisions. The ID group specified that they worried about what college courses to pick or what college to go to:

'Yeah sometimes I do worry about what I'm going to do when I leave school. When the career advisor came in to speak to most of us, she asked what we would do when we actually leave school. I said I would move on to college and just kind of build it up to make my own decisions for myself…But actually having a decision to make is quite difficult.' (Male from the ID group)

The non-ID group also worried about decisions relating to further education, but more often they would state that they struggled with any decisions relating to their future:

'Depending what it is I would say it could be… Just like big things about your future…it's just the big things, big life decisions.' (Male from the non-ID group)

Failure.

The ID group predominantly worried about failure relating to their school-work. This was class work or homework based rather than exams:

'I find homework quite hard. I can write down my words but I find it hard to spell. I can write okay, I can write good, but I find it difficult when my teacher tells me to spell. It's hard to do that.' (Female from the ID group)

The vast majority of the non-ID group who expressed worries about failing spoke about failing exams:

'Yeah because obviously at the end of this year I'm going to be sitting the exams and I will worry then about whether I will fail and whether I'll have good qualifications going through life.' (Male from the non-ID group)

Family.

Family was the 6th biggest worry for the ID group. The majority of participants worried about fights in the family, although this was closely followed by worries about not seeing family as much as they wanted to:

'Fighting. Fights and arguments. Yeah, people spending too much money. He should save up. He's just spending all the money on fags and that. It just wastes it.' (Male from the ID group)

The non-ID group also worried a lot about fights in the family but more of them were concerned about another family member's health. Several spoke about how family members look out for one another with regard to health:

'In case someone becomes unwell and…well in case something happens to someone and they don't want to tell you in case - because they don't want to worry you. But then you don't want them to go through things that they shouldn't go through because they don't deserve it.' (Male from the non-ID group)

Further education.

All of the participants in the ID group attended college for a day or a half-day per week as part of an initiative to ease the transition between school and college. The ID group expressed in equal quantities their fears of not knowing anyone at college and travelling to college independently:

'Yes, independent travel…Yes, I'm very worried about independent travel. If I don't get off the bus or if the bus is late. Or if I don't get to college on time. Because there's no school bus. You can't take anyone to college with you, you can't just go with your family. You have to go by yourself.' (Male from the ID group)

The non-ID group mainly worried about whether or not they would be successful in gaining a place at college or university. Many were also concerned about not knowing anyone when they started their further education placement:

'Well I was hoping to go to college after Uni to do teaching - primary teaching. And I applied, but I didn't have any success. I've still to hear back from two, but so far they've been telling me that I don't have the required grades. But I'm still sitting my Highers to get the grades, so I

don't know how they can say that I don't have the grades…they don't even know what I've got.'

(Female from the non-ID group)

Money.

Money was the 12th most salient worry for the ID group and the 4th most salient worry for the non-ID group. The ID group expressed worry about not having enough money at the moment:

'Yeah, just if I don't have enough money to pay for something or get something.' (Male from the ID group)

The non-ID group expressed worry about not having enough money in the future. Often they linked their concerns to their expectations that their parents would stop paying for them when they reached the age of 18:

'Yes, well not just now but it will be when I leave school. I think because I'm still a child just now, to my mum and that. But when I go to Uni I'll be 18 and I'll obviously not be able to look to my parents so much for money and that.' (Female from the non-ID group)

Between Group Comparisons

Prior to conducting quantitative analyses, the distribution of the rumination, distress and anxiety scores for each of the two groups was tested using the Kolmogorov Smirnov test and also explored visually. This indicated that the anxiety scores for both groups were normally distributed. However, distress scores were only normally distributed for the non-ID group. Rumination scores were not normally distributed for either group. As such, both parametric and non-parametric tests were used in the analyses.

Rumination

Participants rated each of their top 4 worries for rumination on a 3-point scale (where 1=sometimes; 2= often; 3=always). Rumination scores were totalled, giving a total rumination score out of 12. The

ID group's rumination scores varied from 5 to 11, with a median rumination score of 9 (interquartile range = 2.5). The rumination scores for the non-ID group varied from 5 to 12, with a median rumination score of 8 (interquartile range = 2). A Mann-Whitney test showed that there was no significant difference between the two groups' level of rumination (U=324, z= -.252; p >0.05). A small effect size was found (r=0.04).

Distress

Each participant rated their top 4 worries individually for distress on a 3-point scale (where 1=a little; 2=quite; 3=very). Distress scores were totalled, giving a total distress score out of 12. The ID group's distress scores varied from 6 to 12, with a median distress score of 9 (interquartile range = 2). The non-ID group's distress scores varied from 5 to 12, with a median distress score of 8 (interquartile range = 4). A Mann-Whitney test showed that there was no significant difference between the two groups' level of distress (U=271.5, z=-1.231, p >0.05). A small effect size was found (r=0.17).

Anxiety

An anxiety score was obtained for each participant using the GAS-ID. The mean score on the GAS-ID for the ID group was 22.28 (SD=8.37). The mean score for the non-ID group was 17.85 (SD=7.69). An independent t-test showed this difference to be significant: t(50)=1.99; p<0.05. A medium effect size was found (r=0.27).

Within Groups Associations

The Spearman Correlation Coefficient was used to analyse within group associations between rumination, distress and anxiety.

Rumination and Distress

No significant association between rumination and distress scores was found for the ID group: $r_s = .24$, $p > 0.05$. However, a highly significant positive association between rumination and distress scores was found for the non-ID group: $r_s = .5$, $p < 0.01$ indicating a large effect size.

Rumination and Anxiety

No significant association between rumination and anxiety was found for the ID group: $r_s = .29$, $p > 0.05$. However, there was a significant positive association between rumination and anxiety for the non-ID group: $r_s = .34$, $p < 0.05$ indicating a medium effect size.

Distress and Anxiety

There was a highly significant positive association between distress and anxiety for the ID group: $r_s = .54$, $p < 0.01$ indicating a large effect size. There was also a highly significant positive association between distress and anxiety for the non-ID group: $r_s = .55$, $p < 0.01$ indicating a large effect size.

Discussion

The results revealed that there were qualitative differences in the content of the worries experienced by adolescents with mild to moderate IDs when compared to their non-disabled counterparts. Against expectation, there were no significant differences between the two groups in terms of the levels of rumination or distress associated to the worries. However, the ID group were significantly more anxious than the non-ID group. Finally, partial support was found in favour of the final set of hypotheses which anticipated that there would be significant positive correlations between rumination and distress, rumination and anxiety, and distress and anxiety. Significant positive associations were found between all three relationships for the non-ID group, but only between distress and anxiety in the ID group. These results are, for the most part, consistent with the findings of Forte et al's (2011) study.

In accordance with Forte et al's (2011) findings, many of the differences in the content of the worries appear to reflect the different life experiences that the adolescents have had. For example, the ID group's concerns about failure were broad-ranging; they worried about failing to succeed with school-work, about getting into a relationship, getting a job, and in living independently. Fears of failure in the non-ID group tended to be focussed entirely upon academic failure. Differences were also evident when discussing socially-oriented worry topics. There was a sense of personal threat in the social worries of people with ID; for example, they worried about current experiences of being bullied and whether they should trust their friends. These types of concern were not present in the non-ID group who, instead, were more likely to worry about drifting apart from friends once they left school. Moreover, the non-ID group expressed worries about academic achievements, which were rarely mentioned by the adolescents with IDs.

The current study supports previous research that suggests life experience and societal factors influence the content of worry (Forte et al, 2011; Li and Morris, 2007; Cartwright-Hatton, 2006; Vasey et al, 1994). Even at the early stage of adolescence, different life experiences can be seen to differentiate the content of the worries of people with and without ID. The general fear of failure raised by the ID participants may reflect the low expectancy of success that has been found in previous research (Zigler et al, 2002; Zigler and Balla, 1982). In addition, it is notable that participants in this study and in Forte et al's (2011) study both had worries regarding social threat. Goffman (1968) theorised that people with disability recognise that they are devalued by society and accept that devaluation. Given the findings of this study, it does not seem unreasonable to consider whether or not this acceptance is present from as early as the adolescent years. Previous research has found that young people with IDs are aware of the social judgments that are made about them and about the stigmatised position they hold (Jahoda et al, 2010; Cooney et al, 2006). In their study of 39 adults with IDs, Dagnan and Waring (2004) identified that having a sense of 'feeling different' was associated with having negative evaluative beliefs about the self. From these findings, they

surmised that the social world is important to people with ID and that the stigma they are subject to can cause psychological damage.

The quantitative results of this study support the notion that rumination, distress and anxiety are all interrelated components of the phenomenon of worry (Borkovec, 1998; Wells, 1997; Beck et al, 1985). The highly significant correlation between distress and anxiety for both groups provides support for metacognitive theory (Cartwright-Hatton et al, 2004; Mather and Cartwright-Hatton, 2004; Wells, 1997, 1995). This is all the more compelling when considering that Forte et al (2011) also found significant positive correlations in this relationship. Less support is offered for Szabo and Lovibond's (2004; 2002) research, where it was found that higher anxiety related to higher levels of rumination. This picture was found for the participants without IDs, but not for those with IDs. Szabo and Lovibond's research also measured the number of successful problem solving attempts made by participants, and surmised that there was a role for problem solving in reducing rumination and anxiety. Comparing the findings of their research to those from both the current study and Forte et al's (2011) study raises questions as to whether problem solving mediates anxiety and rumination for the ID population, for whom there is no evidence of a significant association between these two features.

Whilst there was no significant difference between the anxiety or distress scores, it should be noted that the adolescents without ID expressed high levels of distress; much more so than was found in Forte et al's (2011) research. It may be, that by the time people without IDs are progressing through college, their increased independence has raised their sense of self-efficacy and they develop a level of mastery over their worries resulting in a reduction in distress. In keeping with this suggestion, Forte et al found that young adults without IDs were significantly more self-efficacious than those with IDs. As with Forte et al's study, there was no significant difference between the two groups in terms of the amount they ruminated, but both groups in both studies reported high levels of rumination. Anxiety scores on the GAS-ID were also high for both groups, with the means of both

sets of scores falling into the clinically significant range (Mindham and Espie, 2003). Whilst caution should be exercised when applying the same cut-off point to a non-ID population, it is clear to see that mainstream education adolescents were still experiencing high levels of anxiety at the time this study was carried out.

Limitations

The current study has extended upon the work of Forte et al (2011) and advanced the understanding of the content and implications of worry for young people with IDs. Nonetheless, there are limitations to these research findings. As it was not possible to recruit 30 participants to both groups, it is possible that the statistical analyses were not suitably powered to identify a significant difference between the two groups with regards to levels of distress and rumination. Furthermore, the gender mix was uneven both within and between groups meaning that the sample was less representative than was originally intended. In terms of the methods, participants were interviewed on their first meeting with the researcher and were seen in their school setting, which imposed a level of formality on the sessions from the outset. Whilst the researcher spent time building rapport with participants, explaining the function of confidentiality and making attempts to reduce the power imbalance, it is possible that participants limited the detail they provided regarding their worries. Similarly, although the worry topics were carefully selected to include the range of worries that have been found to concern children and adolescents, and despite the participants being asked if they had any additional concerns, it is possible that some topics remained uncovered. This may particularly have been the case for more sensitive topics such as sexuality which the participants would be hesitant to raise. Finally, this research captured data at a single point in time and whilst some comparisons can be drawn between the current findings and those from Forte et al's study, these remain speculative given that the samples are different. It would be beneficial to carry out longitudinal work into the development of worry for young people with IDs.

Further Research

As well as employing longitudinal methods to explore the development of worry, there are other interesting findings from this research that would benefit from further investigation. From adolescence, the impact of participants' life experiences were evidenced in the content of their worries. Further research investigating their awareness of stigma and the nature of their self-evaluations would be beneficial. In connection with this, it would be useful to explore the function of these self-evaluations and of worry in itself. Forte et al (2011) proposed that worrying may be adaptive for people with IDs as it may prepare them for real difficulties that they are likely to face. Rates of anxiety were high in their study and in the current research, which could pose a risk for developing mental health disorders. However, as they suggest it may also be that this increased anxiety reflects a heightened awareness of threat and provides the individual with an opportunity to prepare to cope, perhaps through avoidance or by challenging the perceived threat. Further investigations into the link between worry and coping may shed further light on this theory. It has also been proposed that worrying about worry may lead to the association found between distress and anxiety; further exploration of meta-cognitive beliefs in people with mild to moderate IDs would be beneficial in order to understand this link further.

Implications

As described, there are implications for the findings of this study with regards to advancing the evidence base surrounding worry in adolescents with IDs. In addition, there are several clinical implications. This study has unveiled the common worries for adolescents with and without IDs as they approach the transition away from school. Professionals working in schools, social care and healthcare should consider these areas and enquire about them when approaching transition planning with young people. Opening up conversations about these topics will allow an opportunity for professionals to collaboratively explore the concerns with adolescents and potentially find ways to alleviate any associated distress. The Worry Interview in itself may provide a useful tool in which

to facilitate these conversations. The findings regarding worry content can also be used to inform resilience-building programmes if education providers go on to incorporate such programmes into their curriculum. This study would indicate that resilience building programmes should be qualitatively different in order to sensitively meet the needs of adolescents with and without IDs. Finally, the high anxiety scores for adolescents in both groups pose some concern. It would be beneficial for schools to monitor anxiety in their pupils and to consider introducing anxiety reduction or management measures as part of their curriculum.

Conclusions

This study has furthered the evidence-base surrounding worry and provides a starting point for investigating this phenomenon in adolescents with IDs. It has identified the high levels of rumination, distress and anxiety that adolescents can experience as they approach the transition away from secondary school. The finding that the participants with IDs had more worries than their non-disabled peers about their ability to succeed in various aspects of their lives, along with their concerns about social threat, might demonstrate insight into the real challenges that they face. It requires further investigation in order to better understand whether such worries are also linked to negative self-evaluations that increase vulnerability to future mental health problems.

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Table 1: Demographic details for the ID and non-ID groups

Group	Number	Age	Females: Males Gender Ratio	Mean DEPCAT Score	Mean IQ from 2-test WASI
ID	25	Mean = 17.2	10:15	Mean = 5.7	Mean = 64.6
		SD = 0.5		SD = 1.5	SD = 5.9
		Range = 2		Range = 5	Range = 18
		Min = 16		Min = 2	Min = 55
		Max = 18		Max = 7	Max = 73
Non-ID	27	Mean = 16.4	16:11	Mean = 5.8	Mean = 99
		SD = 0.8		SD = 1.5	SD = 7.8
		Range = 2		Range = 5	Range = 32
		Min = 15		Min = 2	Min = 84
		Max = 17		Max = 7	Max = 116

Table 2: Most common worry content for the ID and non-ID groups categorised by worry topic

| Worry Topic	ID Group: Most Common Worry Content	Number people mentioned this (% per group)	Non-ID Group: Most Common Worry Content	Number people mentioned this (% per group)
Death	*Previous experience of loss*	8 (32)	*My own death*	7 (25)
Failure	*That I won't do well with schoolwork (not specific to exams)*	10 (40)	*That I won't do well in exams*	15 (55.6)
Decisions	*About what college & course I should pick*	7 (28)	*Making decisions affecting my future (non-specific)*	8 (29.6)
School	*Leaving school and missing the teachers*	10 (40)	*The exams*	20 (74.1)
	Leaving school and missing my friends	10 (40)		
Relationships	*Trying to get a boyfriend or girlfriend*	7 (28)	*Finding the person who is right for me*	5 (18.5)
Family	*Fights in the family*	4 (16)	*Family members health*	7 (25.9)
Bullying	*Bullying that I'm experiencing right now*	5 (20)	*Other friends or pupils getting bullied at the moment*	3 (11.1)
Work	*That I don't have the skills to get a job*	7 (28)	*That I won't get a job because there aren't many going around*	7 (25.9)
Further education	*Not knowing anyone in college*	3 (12)	*Not getting a place at college/university*	8 (29.6)
	Travelling to college independently	3 (12)		
Health	*Getting ill because it's unpleasant*	3 (12)	*Getting ill because it might affect my academic achievement*	3 (11.1)
Friendship	*That I can't trust my friends*	4 (16)	*That my friends will grow apart in the future*	4 (14.8)
Money	*Not having enough money at the moment*	4 (16)	*Not having enough money for the future*	9 (33.3)
Loneliness	*Not having people to hang around with outwith school*	4 (16)	*Being lonely when I get to college/university*	8 (29.6)
Home	*That I won't be capable of living independently*	4 (16)	*Having troublesome neighbours*	2 (7.4)
Appearance	*Not looking the way I want to look*	5 (20)	*Not looking the way I want to look*	6 (22.2)
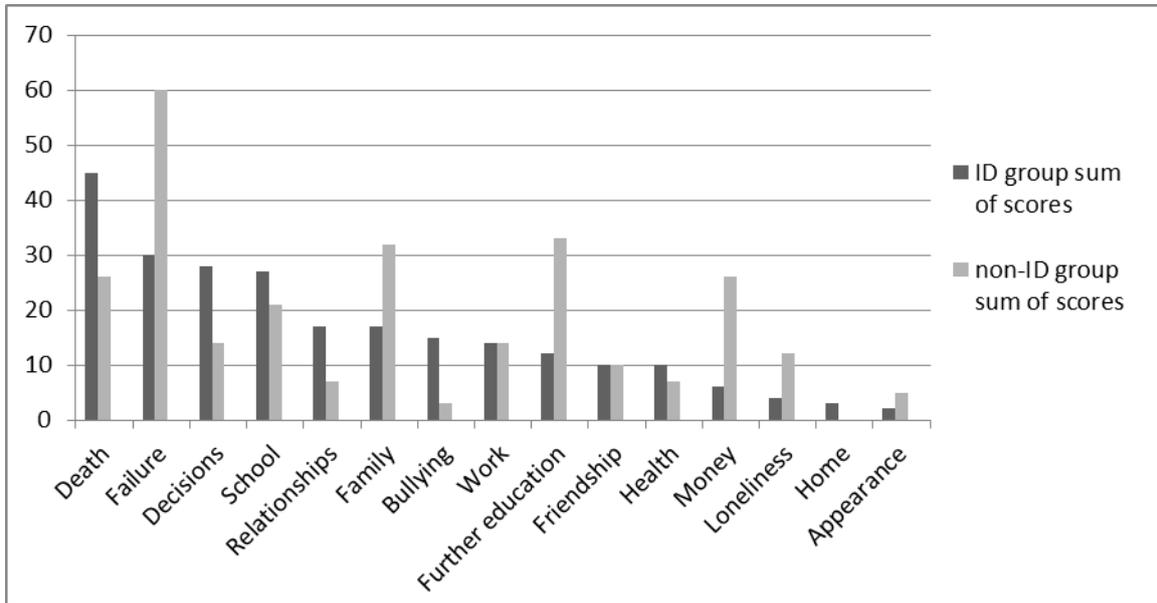
Figure 1: Most salient worries for the ID and non-ID groups

CHAPTER 3: ADVANCED PRACTICE 1 – REFLECTIVE CRITICAL ACCOUNT (ABSTRACT ONLY)

Reflections on the Development and Synthesis of Clinical Practice Skills Across

Three Years of Training in Clinical Psychology

In order to be reflective practitioners, Clinical Psychologists are required to reflect upon the experiences that they have during their working day in order to engender self-awareness, increase autonomy and develop an accurate insight into their own abilities and learning needs. In the following reflective account, I have made use of Stoltenberg et al's (1998) Integrated Developmental Model in order to explore my experience of reflective learning across training. This model describes three levels of development through which a supervisee progresses as they become more self-aware, more autonomous and less self-focussed across training, and as their levels of motivation find an even balance. My reflective account describes the development and synthesis of my clinical practice skills, particularly those of formulation and treatment planning, across the three levels of development. To do this, I have given three examples of cases that I have worked on in the three different years of training. Through the use of Stoltenberg et al's model, I have demonstrated the inter-linking features of how I understood each case and explored the development of my skills within this. I finish with final reflections on the process of writing the account together with a description of some of my future learning needs.

CHAPTER 4: ADVANCED PRACTICE 2 – REFLECTIVE CRITICAL ACCOUNT (ABSTRACT ONLY)

Working Through Others: Reflections on Supporting Staff to Routinely

Enquire About Experiences of Abuse

Within the last five to ten years, the role that Clinical Psychologists can play in working as part of a team has been increasingly discussed and has been recognised in both strategy and professional guidance reports. The current reflective account describes the development of my own competence in training and in working through other team members. My account focuses on one experience of delivering training relating to the Gender Based Violence and Health Programme in Learning Disability Services. Specifically, it reflects on my own reaction to another clinician's discomfort with listening to examples of childhood abuse. I have made use of Gibbs' (1988) Model of Reflection in order to structure this account. Gibbs' model describes six steps that prompt practitioners to explore their feelings and thoughts relating to the learning experience, to evaluate the experience and draw conclusions, before then formulating an action plan as to how they would develop or change their practice in the future. The current reflective account concludes with final reflections on the process of writing about my reflections on this subject.

Appendix 1.1: Copy of Guidelines for Authors for Submission to the Journal of Applied Research in Intellectual Disabilities

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The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship. It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

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Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

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Appendix 1.2: Cluster One First-Order Constructs Grouped by Study Under the Headings of Second-Order Constructs (themes)

Studies \ Themes	Frustration at limited opportunities	Remaining an advocate	Feeling like an outsider	Finding the balance	Teaching adulthood
Cooney (2002)	Options that are offered do not help their offspring to meet their full potential; rarely offered a chance to contribute positively.	/	Troublesome experiences relating to learning the ins and outs of an unfamiliar system. Feeling like 'foreigners' at transition meetings; uncertain outcomes, unfamiliar transition terms and procedures, and; unexpected barriers contribute to feelings of powerlessness.	/	Using transition meetings to demonstrate how to utilise their offsprings' strengths to meet goals. Identifying what is important to them and shaping support around this
Docherty and Reid (2009)	/	Mothers alluded to their on-going role in the lives of their offspring as crucial and indispensable. There is a requirement for them to continue to engage with the outside world on their behalf.	/	There was a sense that they had to push both themselves and their offspring towards a goal of independence, in terms of life and work. There was concern that they had to be prepared to challenge the natural parenting role of protecting their offspring. Mothers appeared to be striving for a balance between encouraging change whilst also recognising the current abilities of their offspring	Finding a way to define and shape a concept of adulthood with their offspring through teaching independence and autonomy.

Bianco et al (2009)	Parents discussed the lack of available service options after their child left school.	Advocating for services that are required and for their child's independence.	Many parents did not always feel their relationships with agencies and service providers were welcomed or collaborative. Service providers did not fully appreciate the value of their contributions as collaborators, but still depended upon them to fill the gaps.	Needing to relinquish control but observe and step back in as required. Always striving for a balance. Although they sought for independence, self-advocacy and self-determination for their child, this was mediated by the child's on-going need for assistance.	Parents talked about how they provided instruction, training and supervision for their offspring and for service providers. Roles in teaching job related skills to their child and also about self-advocacy. Training service providers about how to support their offspring.
Gillan and Coughlan (2010)	Stress and anxiety over the lack of certainty of options. Helplessness evoked by the lack of alternatives in terms of available adult services.	Feeling like the parent's role as an advocate facilitates transition. Families' experiences were partly characterised by fighting or battling for their offspring as they negotiated different services and support systems trying to obtain jobs.	Frustration in dealing with inflexible and unresponsive services. Disempowerment. Lack of facility to be involved with transition planning or with adult services emerged as a significant source of stress.	Parent's own reluctance to provide the child with opportunities for independence. The child's vulnerability and cognitive difficulties were identified as a significant barrier. Fear of money difficulties and being led by others.	Parents described teaching their children skills to facilitate the transition to adulthood – how to manage money appropriately, use phones and complete adaptive self-care tasks.

Appendix 1.3 Cluster Two First-Order Constructs Grouped by Study Under the Headings of Second-Order Constructs (themes)

Themes / Studies	Frustration at limited opportunities	Feeling like an outsider
Rapanaro et al (2008)	Parents voiced feelings of helplessness and sadness regarding lack of opportunities for child (i.e. social relationships).	Parents identified the loss of freedom and independence they experienced and considered how this was likely to continue into their son or daughter's adulthood. Some parents felt resentful when comparing themselves to families without a young person with an ID. Parents described gaining a new realisation and acceptance of their child's ability as they entered adulthood and revised their expectations regarding their future.
Davies and Beamish (2009)	Parents expressed frustration at the lack of opportunities for their young person since they left school and the lack of appropriate finances needed to support independence and activity.	Parents spoke about the impact of transition, particularly for mothers, many of whom gave up work or reduced their hours. They spoke about resenting the changes that they have had to make in adjusting to this period in their child's life.

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Title Page: Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process**. However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

Keywords: The author should also provide up to six keywords to aid indexing.

Abstracts:For full and brief reports a structured summary should be included at the beginning of each article, incorporating the following headings: Background, Method, Results, and Conclusions. These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

Optimizing Your Abstract for Search Engines: Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimizing your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximize the web-friendliness of the most public part of your article.

5.3. References

The Journal follows the Harvard reference style. References in text with more than two authors

should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood.
- Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research***24**, 137- 41.
- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here: www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here: www.refman.com/support/rmstyles.asp

5.4. Tables, Figures

Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and give a short caption.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

Preparation of Electronic Figure for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). Please submit the data for figures in black and white or submit a Colour Work Agreement Form (see Colour Charges below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

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John Wiley & Sons Pte Ltd require you to complete and return a Colour Work Agreement Form before your paper can be published. Any article received by John Wiley & Sons with colour work will not be published until the form has been returned. If you are unable to access the internet, or are unable to download the form, please contact the Production Editor (jir@wiley.com)

Appendix 2.2: Examples of Photographs Used to Represent Worry Topics in the Worry Interview

APPEARANCE:

HOME:

RELATIONSHIPS:

MONEY:

Appendix 2.3: Examples of the Rumination and Distress Scales
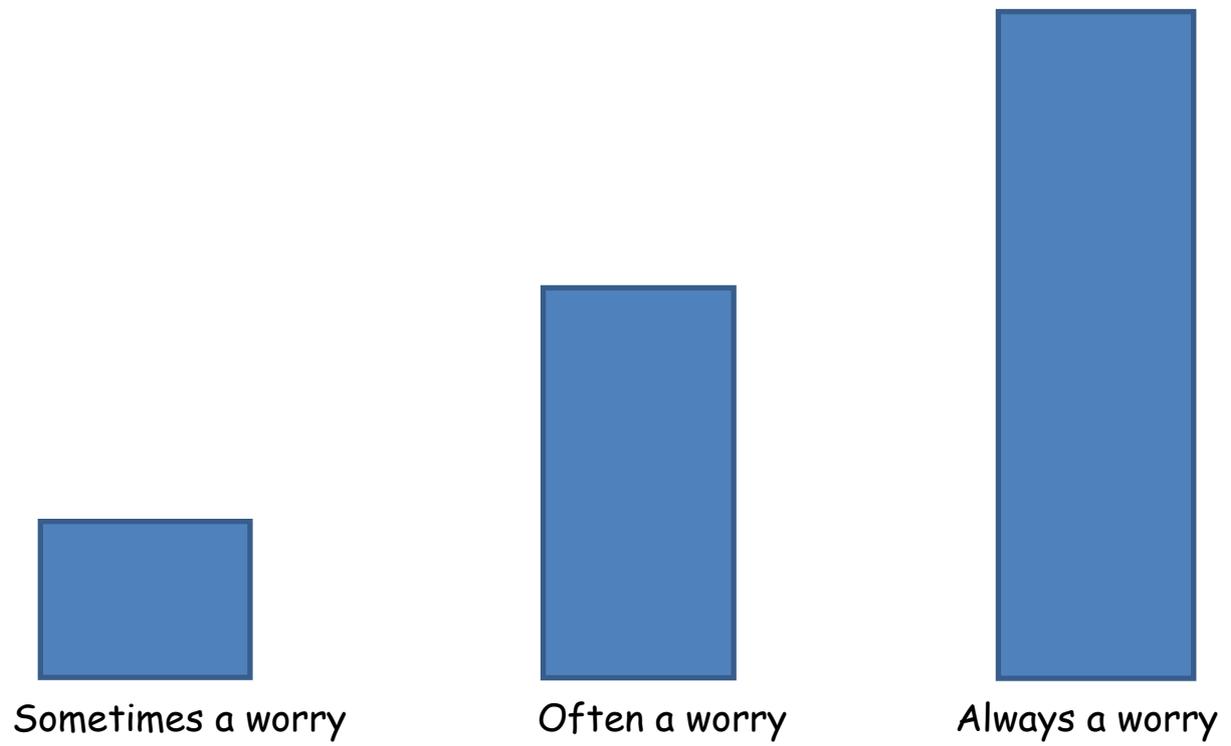
Sometimes a worry   Often a worry   Always a worry

A little bit upset   Quite upset   Very upset
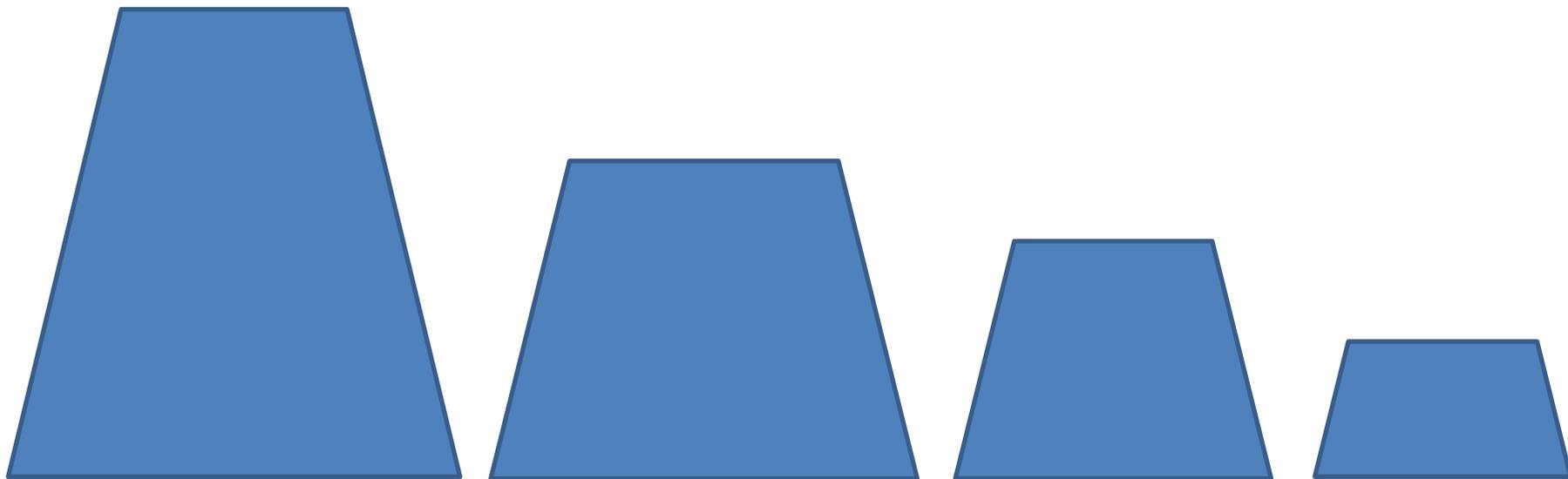
Appendix 2.5: Copy of the Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID)

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

Worries

1. Do you worry a lot? *(…feel worked up/wound up/uptight/up to high doh)*

2. Do you have lots of thoughts that go round in your head? *(…thoughts that you can't stop/come from nowhere)*

3. Do you worry about your parents/family?

4 Do you worry about what will happen in the future? *(tailored to the individual; e.g. What will happen if you can't live with your mum anymore?)*

5. Do you worry that something awful might happen?

6. Do you worry if you do not feel well? *(…if you feel sick)*

7. Do you worry when you are doing something new? *(…like for the first time)*

8. Do you worry about what you are doing tomorrow?

9. Can you stop worrying? (reverse score)

10. Do you worry about death/dying?

Specific fears

11. Do you get scared in the dark*? (…think of being in bed with the lights out: Would you be scared?)*

12. Do you feel scared if you are high up? *(…think of being up a high building…)*

13. Do you feel scared in lifts or escalators? *(Would you go in?)*

14. Are you scared of dogs? *(Would you stroke/clap?)*

15. Are you scared of spiders? *(Would you go near?)*

16. Do you feel scared going to see the doctor or dentist?

17. Do you feel scared meeting new people?

18. Do you feel scared in busy places? *(…like crowds, shopping centre)*

19. Do you feel scared in wide open spaces? *(…nothing round about you)*

Physiological symptoms

20. Do you ever feel very hot or sweaty? *(…all hot and bothered)*

21. Does your heart beat faster?

22. Do your hands and legs shake?

23. Does your stomach ever feel funny, like butterflies?

24. Do you ever feel breathless? *(…hard to breathe/out of breath)*

25. Do you feel like you need to go to the toilet more than usual? *(…for a 'pee')*

26. Is it difficult to sit still? *(…feel you can't sit at peace)*

27. Do you feel panicky? *(…get into a panic/a 'state')*

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

15 October 2013

Dear RUTH YOUNG

MVLSCollege Ethics Committee

Project Title: A comparison of the nature and severity of worries held by young people with and without intellectual disabilities as they approach the transition away from school
Project No: 2012079

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. They are happy therefore to approve the project, subject to the following conditions

- The research should be carried out only on the sites, and/or with the groups defined in the application.

- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.

- If the study does not start within three years of the date of this letter, the project should be resubmitted.

- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Andrew C Rankin
College Ethics Officer

Most common themes in:

	% of people who mentioned the following
Worries about appearance	
Worrying about not looking the way I want to look	20
Worrying about my appearance not being well thought of	12
Worrying about looking unappealing to potential romantic partners	8
Worrying that I'll make a bad first impression	8
Worries about further education	
Worrying that I'll not know anyone at college	12
Worrying about travelling to college independently	12
Worrying about being in a different and less familiar setting	8
Worrying about struggling with work at college	8
Worries about making decisions	
Worrying about what course and college to pick	28
Worrying about what job I should do	16
Worrying about making decisions affecting my future (non-specific)	16
Worrying about all types of decision	16
Worrying about family	
Worrying about fights in the family	16
Worrying about not getting to see my family as much as I want to	12
Worrying about family members health	8
Worries about health	
Worrying about getting ill because it's unpleasant being ill	12
Worrying about having to take medication	8

Worrying that I'm the type of person who always gets ill	8
Worrying that I'll have to take time off school when I'm ill	8
Worrying about other people being ill	8

Worries about loneliness

Worrying about not having people to hang around with outwith school	16

Worries about relationships

Worrying about trying to get a boyfriend or a girlfriend	28
Worrying that other people will judge me for being single	8
Worrying about finding the person who is right for me	8
Worrying about what to do if someone asks me out	8

Worries about work

Worrying that I don't have the skills to get a job	28
Worrying that I don't know what I want to do	20
Worrying that I won't have the right skills to succeed once I'm in a job	16
Worrying I won't get a job because there aren't many going around	12

Worries about bullying

Worrying about bullying that I'm experiencing right now	20
Worrying that I'll be bullied in the future	16
Worrying about previous experiences of being bullied that I've had	12

Worries about death

Worrying about previous experiences of loss	32
Worrying about my own death	12
Worrying about family members death	12

Worries about failure

Worrying that I won't do well with schoolwork (not exams)	40
Worrying that I won't do well in exams	16

Worrying that I won't do well when I get a job   16

Worries about friends

Worrying that I can't trust my friends   16

Worrying about not seeing my friends once I leave school   12

Worrying that I will grow apart from my current friends in the future   12

Worries about home

Worrying that I won't be capable of living independently   16

Worries about money

Worrying about not having enough money at the moment   16

Worrying that I can't count money   8

Worrying that I'll lose money that I'm given   8

Worries about school

Worrying about leaving school and missing the teachers   40

Worrying about leaving school and missing my friends   40

Worrying about leaving school and losing the support I get there   12

Worrying about getting into trouble at school   12

Appendix 2.8: Common Worry Content in the Non-Intellectual Disability Group

Most common themes in:

	% of people who mentioned the following
Worries about appearance	
Worrying about not looking the way I want to look	22.2
Worrying about looking like I 'fit-in'	11.1
Worries about further education	
Worrying that I won't get a place at college/university	29.6
Worrying that I'll not know anyone at college/ university	22.2
Worrying about not knowing what I want to do at college/university	18.5
Worries about making decisions	
Worrying about making decisions affecting my future (non-specific)	29.6
Worrying about making any type of decision	22.2
Worrying about what course and college to pick	14.8
Worrying about family	
Worrying about family members health	25.9
Worrying about fights in the family	22.2
Worrying about whether I'll have my own family one day	7.4
Worrying about how my family will cope in their lives	7.4
Worries about health	
Worrying that getting ill will affect my academic achievement	11.1
Worrying about other people being ill	7.4
Worrying about being as healthy as I can possibly be	7.4
Worries about loneliness	
Worrying about being lonely when I get to college/university	29.6

Worrying about how I can include myself in conversations   7.4

Worrying about being lonely in the workplace   7.4

Worries about relationships

Worrying about finding the person who is right for me   18.5

Worrying about experiencing stress once I'm in a relationship   7.4

Worries about work

Worrying I won't get a job because there aren't many going around   25.9

Worrying about ending up with a career that isn't what you wanted   7.4

Worries about bullying

Worrying about other pupils getting bullied at the moment   11.1

Worrying that family members might get bullied   7.4

Worries about death

Worrying about my own death   25.9

Worrying about family members death   22.2

Worrying about previous experiences that I've had of loss   18.5

Worries about failure

Worrying that I won't do well in exams   55.6

Worrying that I'll fail at something that I've tried hard at   18.5

Worries about friends

Worrying that my friends will grow apart in the future   14.8

Worrying that I won't have enough time to see my friends because of school pressures   7.4

Worries about home

Worrying about troublesome neighbours   7.4

Worries about money

Worrying about not having enough money in the future   33.3

Worrying about not having enough money at the moment	25.9
Worrying about my parents being stressed about money	7.4

Worries about school

Worrying about the exams	74.1

Abstract

Background: The proposed study plans to investigate the content and nature of the worries that young people with and without intellectual disabilities (IDs) have as they approach the transition away from school. *Methods:* Sixty participants will be recruited; 30 will have mild-moderate IDs and 30 will not. All participants will be aged 15 or over and will be attending local authority schools. Each participant will complete a semi-structured worry interview which will record the content of their worries and measure the level of rumination and distress each of these worries cause. In addition they will complete the Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-LD; Mindham and Espie, 2003). Worry topics will be content analysed and comparisons will be made between the two groups to identify any similarities or differences. A between-subjects analysis will explore differences between the level of rumination, distress and anxiety experienced by the two groups. Within-subject comparisons will investigate the relationship between anxiety, rumination and distress for each of the groups. *Implications:* It is anticipated that this study will shed light on the worries experienced by young people with IDs as they approach transition. This will inform the research base about the implications of worry in terms of distress, rumination and anxiety, and possibly indicate influences on worry, such as aversive life events. It is expected that this information will be useful when developing appropriate social and psychological supports for the transition phase, which may increase psychological resilience and decrease stress at this time.

Borkovec (1983) defines worry as consisting of a chain of repetitive verbal thoughts and images about possible future negative outcomes and about what the consequences of those outcomes could be. It has been suggested that worry is a useful part of the problem-solving process (Szabo and Lovibond, 2004, 2002); however, it also appears to play a key role in the maintenance of anxiety disorders (Holaway et al, 2006). With these potential functions in mind, it is clear that worry is an important feature of mental well-being. Despite this, whilst there is a burgeoning evidence base of worry in the general population, little is known about the development and content of worries amongst adolescents with intellectual disabilities (IDs). In order to develop the evidence base in this area, it is important to know what it is that adolescents with IDs worry about, how distressing and perseverative these worries are, and whether these worries link to an increase in anxiety.

Research carried out to date has identified that there are roles for age, life experience and societal factors in determining the content of worry. In childhood, worries are found to be concrete and centred on physical safety, whereas in adolescence, they are more abstract and concerned with social-acceptance and psychological well-being. Vasey et al (1994) links this finding to the development of increasingly complex self-concepts. Various studies have found an effect of life experience or societal influences. Li and Morris (2007) found that older male adolescents with IDs had a higher level of fear associated to failure and criticism when compared to older females. They hypothesised that older males are exposed to more disparagement from their peers because of their disability and received less protection from adults because of their male status. It may be that Li and Morris surmised that general population adults hold stereotypical views that males are less sensitive than females, that they have more robust self-esteem and are less interested in how their peer group view them. Forte et al (2011) found a similar picture when they explored the worries of participants with and without IDs during the transition phase away from college. Using a semi-structured 'worry interview' that was enhanced by the use of pictorial aids, they found significant differences in the content of the worries of their two participant groups that appeared to reflect

differences in their previous experiences or current social circumstances. For example, the ID group's fear of death related to losing someone they were close to and the worry about how they could cope by themselves; whereas the non-ID group feared their own deaths. Similarly, whilst very few people with IDs were being bullied at the time of the study, previous experience of bullying left them with worries that they would be bullied again.

It is important to understand the content of worry in order to shape assessment tools and put in place appropriate social supports or problem-solving interventions. Transition from secondary school can be a particularly stressful time for young people with IDs. Within England and Wales, positive advances have been made to address the practical needs of young people with IDs as they approach transition which recognise a need for more information and more choice about where they can go on leaving school (Ofsted, 2011; SCIE, 2004). However, their emotional needs have been widely ignored. As highlighted by Forte et al (2011), transition is a time where identity is shaped and independence is increased. For people with IDs, these developmental tasks are already complicated: their needs may increase at transition when they lose the support of a full-time education placement and experience uncertainty over whether they will get a job or college placement. This can have significant repercussions for their emotional well-being. Forte et al (2011) identified that college students with IDs experience more distress, more rumination and higher levels of anxiety in comparison to their non-ID peers, which may reflect some of the adversity that they face at this time. The Social and Emotional Aspects of Learning programme (Department for Education and Skills, 2007) has been developed in England and Wales with the aim of increasing young people's emotional resilience before they leave secondary school education. However, this tool is aimed at pupils who do not have IDs, and it is likely to have limited use to pupils with IDs if there are differences in the content of worries at this time.

As previously mentioned, the intensity and frequency of worries experienced by adolescents with IDs is a particularly important area for further research. It has been consistently found that it is the

intensity of worry that differentiates non-pathological from pathological worry (Cartwright-Hatton, 2006). Distress and rumination scores correlated with anxiety scores in Forte et al's study (2011). At present, it is unclear why this link exists. A possible hypothesis suggested by Szabo and Lovibond (2004, 2002) is that pathological worriers are unable to problem-solve their worries and so experience more distress from the process of worry. Recent research about the link between meta-cognitive beliefs around worry (such as believing worry is dangerous) may also explain why distress and pathological worry are linked. Another possibility, which is of particular relevance to people with IDs, is that increased distress may be linked to a reduced expectancy of success and a sense of helplessness, which is highlighted as being a common motivational feature in IDs by Zigler et al (2002; 1982) and which can be associated with an increased likelihood of developing emotional disorders.

It is clear that more needs to be understood about the emotional implications of the transition process away from secondary school. The work of Forte et al (2011) has identified that people with IDs have very real concerns about the transition away from college which differ from those held by their non-ID peers. However, it is not clear as to whether these concerns are also present during the earlier transition from school; nor is it clear whether these worries have as significant an impact upon levels of distress, rumination and clinical anxiety as they did with the older cohort. It is vital to clarify this in order to understand the impact of transition for adolescents and, in turn, for appropriate social and psychological supports to be put in place that may be able to increase their psychological resilience and reduce the risk of developing mental health difficulties.

Research Aims

The aim of the current research project is to develop an understanding of the worries that young people with IDs have in the approach to transition. The project intends to investigate whether there are any differences in the content or nature of these worries that may reflect differences in their life experiences when they are compared to a non-ID control group.

Hypotheses

    A. There will be differences between the ID and non-ID groups in terms of:

        i) The types of worries they have;

        ii) The level of rumination will be higher for the ID group than non-ID group;

        iii) The level of distress will be higher for the ID group than the non-ID group;

        iv) The levels of anxiety experienced will be higher for the ID group than the non-ID group.

    B. There will be positive correlations within the ID and non-ID groups in terms of:

        i) The level of distress and rumination experienced in association to the worries;

        ii) The level of distress and anxiety experienced in association to the worries;

        iii) The level of rumination and anxiety experienced in association to the worries.

Participants

All of the participants will be in the transition planning phase of their education, which begins at age 15. Approximately 30 adolescents with mild to moderate IDs will form an experimental group and 30 adolescents who function within the normal range of intelligence will act as a control group. As far as possible the two groups will be similar in terms of age, gender and socio-economic status.

Justification of Sample Size

This is predominantly an explorative study into the worries of pre-transition adolescents with IDs. There is also a between-subjects quantitative component and so there is a need to estimate a suitable sample size. The quantitative component will use the same methodology and measures as were used in Forte et al's (2011) study to investigate for differences in rumination and distress

between young people with and without IDs. Using t-tests, Forte et al (2011) found a medium to large effect size of 0.65 for the differences between the ruminations scores of adults with and without IDs. A large effect size of 1.38 was found for the differences between scores on the distress measure. It is reasonable to assume that the current study will have similar effect sizes as found in the Forte et al (2011) study. Using the smaller of the two effect sizes (0.65) for the current study, it is estimated that 30 participants per group will be required to detect a significant difference between scores on a Likert scale measure of rumination. Using the larger effect size (1.38), it is estimated that 8 participants per group will be required to detect a significant difference on a measure of distress. Both calculations are based on an alpha level of 0.05 and a power of 0.8 (one-tailed). As such, the current study will aim to recruit 30 participants to each group.

Inclusion Criteria

Participants will be included in this research project if they:

- Are able to provide informed consent.

- Are English speaking.

- Have reasonable verbal communication as determined by the following verbal components of the Adaptive Behaviour Scale (ABS-RC: 2; Nihira, Leland and Lambert, 1993):

    1. Talk to others about sports, family, group activities etc.

    2. Sometimes use complex sentences containing 'because', 'but' etc.

    3. Answer simple questions such as 'What is your name?' or 'What are you doing?'

Exclusion Criteria

Participants will be excluded from this research project if they:

- Have a degree of sensory or physical impairment (e.g. significant visual impairment) that will mean they are unable to complete the tasks.

Recruitment

Participants will be recruited from special education and mainstream schools in the West of Scotland. The researcher will contact the head teachers of each of the schools and request a meeting to discuss the research project. Teachers will be asked to identify pupils who meet the study's criteria before information sheets will then be sent, by the researcher, directly to the pupil. The researcher will also offer to speak to groups of suitable participants to tell them about the study. Thereafter, informed consent will be gathered from those young people who wish to participate.

Design

This is an exploratory study on the nature of worries which uses between and within-group components to help identify and establish the impact of worry in terms of distress, rumination and anxiety for adolescents with and without IDs.

A between-subject design will be used to qualitatively explore and compare the most salient worries experienced between the groups in order to identify if there are any similarities or differences. The same design will then be used to quantitatively explore the differences between the levels of distress and rumination caused by these worries, and between the levels of anxiety experienced.

A within-subjects design will be used to quantitatively explore correlations between the distress, rumination and anxiety scores for the ID and control groups in order to identify whether these factors are associated with one another.

Measures

Several measures, all of which have previously been used with people with and without IDs, will be used in this research project. The measures that will be used are listed below in the order that they will be administered:

5) A background information sheet will be used to collect information on each participant's age, gender, socio-economic status and educational status. Socio-economic status will be determined using the Carstairs Index (Carstairs and Morris, 1991). This allows a person's status to be rated on a scale of 1-7, where 1 represents the most affluent postcode and 7 represents the most deprived.

6) The 'Worry Interview' will be used to gather information on the participants' most salient worries and the extent of the distress and frequency of rumination caused by these worries. The 'Worry Interview' was devised by Forte et al (2011) for a study investigating the worries of college-attenders. It uses a semi-structured format and pictorial representations of carefully identified 'worry topics' to establish a dialogue about the participants' worries. Participants are shown a picture of a worry topic (such as a picture representing a work place) and asked, "what is this picture of?" and then, "what does this picture make you think of?" Worry topics will be presented in a randomised order across participant groups with the purpose of avoiding order effects. After the participants have had an opportunity to talk about each of the photographs, they are asked to place the pictures in one of two piles; either a pile that represents 'yes, this is a worry for me just now' or 'no, this is not a worry for me just now'. For each photograph in the 'yes' pile, participants are asked to rate on a 3-point Likert scale how much they currently worry about the topic and how thinking about the topic makes them feel, in order to provide a measure of rumination and distress.

Participants then select their 4 most salient worries from the 'yes' pile and range them from 1-4. Forte et al (2011) identified that the Worry Interview elicited responses that could be analysed and grouped with 100% inter-rater reliability.

Prior to the main interview, a pilot study of the Worry Interview will be carried out with 2 adolescents with IDs who will not be included in the main study. The purpose of this pilot is to identify whether any adaptations will need to be made to the Forte et al (2011) study to make it more applicable to a younger population. Forte et al carefully selected their worry topics from a study conducted by Miller and Gallagher (1996) which investigated the worries of adolescents. Additional worries that can be experienced by younger children and adolescents, as identified by Silverman et al (1995), will also be included in the pilot in order to explore whether they should be incorporated into the original Worry Interview. The pilot will also inform the researcher how long the Worry Interview will take to complete with a younger population in order for later testing sessions to be planned appropriately.

7) The Glasgow Anxiety Scale for People with a Learning Disability (GAS-ID) will be used to measure the participants' levels of anxiety. This 27-item scale was developed by Mindham and Espie (2003) specifically for use with ID populations. It has good test-retest reliability correlations of 0.95, good internal consistency of 0.96 and produces reasonable convergent validity correlations with the Beck Anxiety Inventory of 0.75. The scale takes approximately 5-10 minutes to administer.

8) The two subtest form of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) will be used. The WASI links to the Wechsler Intelligence Scale for Children – 4th Edition (WISC-IV; Wechsler, 2003) in order to provide a measure of full scale intellectual functioning (FSIQ). In its two subtest form, the WASI consists of the tests 'Vocabulary' and 'Matrix Reasoning'. Psychometric properties of both subtests and the overall 2-subtest-FSIQ are reasonable. Convergent validity correlations between the WASI and WISC-IV are 0.79 for

Vocabulary, 0.71 for Matrix Reasoning and 0.83 for the overall 2 subtest FSIQ. Test retest

reliability correlations are also good for children completing both the Vocabulary subtest

(0.85) and the Matrix Reasoning subtest (0.77). The two subtest form takes approximately

15 minutes to administer.

Procedure

The interview sessions will take place in a private room within the participant's school. It is

anticipated that each session will last approximately 40 minutes. To encourage the participants to

feel that they can be open during both the Worry Interview and when completing the self-report

measure, the formal cognitive test, which has right and wrong answers, will be undertaken last.

There will be opportunities for the participants to take breaks as necessary or for sessions to be split

across two days where needed in order to maintain the participants' engagement and attention.

Analysis

The qualitative data from the pilot stage will be analysed so that the themes can then be

represented by photographs in the main study. In the main study, the Worry Interviews will be

explored using content analysis (Strauss, 1987). This will allow the qualitative data from the Worry

Interview to be grouped into categories that represent the topic areas that have been spoken about

and for the most salient worries to be described.

To examine the difference between the two group's rumination, distress and anxiety scores

independent t-tests will be used. Within-group associations between the distress, rumination and

anxiety scores for both the ID and control groups will also be explored with Pearson's correlation. If

the data does not meet parametric assumptions, the appropriate non-parametric tests will be used

instead.

Health and Safety

Participant issues

It is anticipated that the participants' safety will not be affected by this research as it will be conducted in their usual environment during normal school hours. Prior to the commencement of the study, the researcher will identify a suitable room and contact person in conjunction with the school or head teachers. The teacher's support will be immediately sought if any concerns arise.

Researcher issues

The researcher will become familiar with safety protocol regarding fire alarms and have an awareness of how to contact nearby staff should the need arise.

A health and safety form has been completed for approval by the researcher's training programme.

Ethics

Ethical approval and permission will be sought separately from NHS Greater Glasgow and Clyde Ethics Committee and the local area Research and Development services before data collection begins.

The interview sessions are designed to be engaging and enjoyable for the participants. It is expected that the participants will welcome the opportunity to talk about their worries and to be listened to, as has been the case in previous research of a similar nature (Forte et al, 2011). However, if the participants become upset at any point when talking about their worries then the researcher, who is a supervised Trainee Clinical Psychologist, will discuss this with them in the first instance and inform a relevant support person. In the case of significant distress or worry, the researcher will recommend that the relevant support person contacts the participant's parental guardian or GP if appropriate. Care will be taken at the end of each session to debrief the participant.

A lay summary of this proposal will also be made available for comment by the Carers and Users of Services in Clinical Psychology Training (CUSP) review panel.

Financial issues

The equipment required to carry out this study will be borrowed from the training programme. In addition WASI forms will be used to estimate intellectual ability.

Timetable

April 2012 – Submit final research proposal

July - September 2012 – Obtain Ethics and Research and Development service approval

October 2012 – February 2013 – Recruitment and data collection

March 2013 – Data analysis

July 2013 –Submit final report

Practical Applications

As far as the researcher is aware, the content and the nature of worries of young people with IDs have not been explored. The proposed study will provide an understanding of these issues and a sound platform for further research to develop from. It will also investigate the utility of using a semi-structured interview to facilitate discussion with adolescents about the content of their worries, which may have value to a clinical setting. Furthermore, the information that is gained on the content of worries can help inform supports that may need to be put in place as the young people approach the complex transition phase.

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