THE UNIVERSITY OF HULL

Families of People with an Intellectual Disability: Exploring the Positives

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

in the University of Hull

by

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June 2017

Acknowledgements

There are many people I would like to thank for their help throughout the course of this project.

Firstly, the participants who gave their time and experience to make the project possible and, without whom, I would not have been able to complete this work. I am eternally grateful.

Second, the anonymous lecturer who unknowingly prompted several participants to contact me and got the ball rolling with my data collection.

Third, my friends, near and far, old and new, who have provided fun and beer on tap for the last few years and given me numerous experiences to look forward. You know who you all are.

Fourth, my family who have given me the means and support throughout my life to reach this point, I know how privileged I am to be here, as well as providing me with a home to return to where there is peace, quiet and a pub quiz nearby. My three grandparents also deserve a mention for their reassuring phone calls and support throughout.

Fifth, my partner who, luckily enough, is much, much smarter than me and has been able to give me excellent advice throughout this project while also providing me with support, constant reminders and, most importantly, lots and lots of fun.

Finally, I would like to thank my supervisor, Dr Nick Hutchinson, who has been a relaxing and reassuring fixture throughout this project, providing constant help and support. I would also like to thank all the staff at the university, particularly Chris and Emma, who gave me the initial inspiration for this project, Tim, for the excellent

guidance and teaching we have received, Anjula for her consistent check-ins as my Personal Tutor and Philip, for his encouragement and support as my Clinical Tutor.

Overview of Research

This portfolio thesis is comprised of three sections: a systematic literature review, an empirical study and a list of appendices.

Part one is a systematic literature review in which a thematic synthesis has been completed to interpret and outline the data from studies which have highlighted positive states and experiences qualitatively reported by non-disabled relatives of people with an intellectual disability (ID). This review rejects the pathological and negative theme across much of the ID literature and, particularly, the literature around family members of people with ID. A systematic search of several electronic databases was completed and 15 studies were included in the review based on a set of inclusion criteria. Three superordinate themes were generated: 'growth', considered change from a subjectively less desirable state to a more desirable state; 'joy', which describes participants' positive, joyous and proud moments associated with their disabled relative and 'developing ways to cope', which describes mechanisms participants use to help them cope with the inherent stresses associated with ID. The implications of these findings are discussed and an assessment of methodological quality is completed to contextualise the findings.

Part two is an empirical paper exploring the lived experiences of personal growth for adult siblings of people with ID. Interpretative Phenomenological Analysis (IPA) was used to understand the participant's subjective experience and how they made sense of it. Seven semi-structured interviews were completed. Three superordinate themes emerged from the data: 'developing strength', which describes participants developing acceptance and resilience and advocating for their sibling; 'learning opportunities', which described participants learning skills and developing values and 'family closeness', which describes participants' closeness with their families and pride in their disabled sibling. These findings are discussed in relation to implications for the literature in ID and the wider societal context.

Part three is a list of appendices from both the literature review and empirical paper.

Total Word Count: 13,601

Contents

List of Tables and Figures

Positives for family members of people with an intellectual disability: A systematic literature review

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This paper is written in the format ready for submission to the *Journal of Applied Research in Intellectual Disabilities* (see Appendix A for submission guidelines).

Word count: 6999

Abstract

Introduction

Research surrounding families of people with ID have followed a timeline of researching the negative, then researching positive from negative and finally researching the positives for relatives of people with ID. This review aimed to synthesise positive experiences of family members of people with ID.

Method

A literature search was completed and thematic synthesis used to generate themes from the findings of the included studies.

Results

Three superordinate themes were generated: ‘Growth’, incorporating personal growth, change in life perspective and increased family strength; ‘joy’, encompassing pride in the disabled relative and seeing the disabled relative as a treasure; and ‘developing ways to cope’, incorporating spirituality, acceptance, strength and developing support systems.

Conclusions

The findings suggest that family members experience positives resulting from challenging experiences but that they also experience positives through unique, often joyous, experiences.

Introduction

Intellectual disability (ID) can be defined as a significantly reduced ability to understand new information, coupled with reduced ability to cope independently, with these difficulties beginning before the age of 18 (Department of Health, 2001). Since researchers began exploring the experiences of family members of people with ID, there have been significant changes in the focus of the research. Originally, studies focussed largely on negative aspects of supporting or living alongside somebody with an ID. Solnit and Stark (1961) wrote about the impact on mothers, stating that a mother must mourn for the loss of the "normal child". Further studies have observed that having a child with an ID is a psychologically stressful experience for mothers (Cummings, Bayley & Rie, 1966) and Johns (1971) noted the absence of normal satisfaction from childbirth in mothers of children with ID. Fathers, too, were found to express more negatives if their offspring had an ID. Cummings (1976) found that fathers of children with intellectual disabilities scored higher for depression, had lower self-esteem and enjoyed parenthood less than fathers of non-disabled children.

There was also significant research into the negative aspects for non-ID siblings of people with ID. Breslau, Weitzman and Messenger (1981) found that siblings of children with ID scored higher for delinquency and mentation (mental activity, portrayed here as a negative), as well as "fighting", when they were screened psychiatrically. Further, Gath (1973) had parents and teachers screen siblings of children with Down Syndrome for psychological adjustment, and found these siblings scored significantly higher than a control group for deviance.

Research into the negatives has continued more recently (Murphy, Christian, Caplin & Young, 2006; Dyson, 2010) but, over time, the literature base has shifted to focus upon resilience in families, and how they cope with and adapt to the stress associated with having someone with an ID in the family (Hodapp, 2005). Models of family coping emerged including McCubbin and Pattersons' (1983) Double ABCX Model, suggesting parental perceptions of the child and internal and external coping resources mediate the impact the stressor (the child) has on the family unit. Consistent with this, Minnes (1988) studied families containing a child with an ID and found characteristics of the child and families' crisis-meeting resources were significant predictors of stress.

Through such models arose research into what allows families to cope in the face of adversity. For example, Gardner and Harmon (2002) explored resilience in six mothers who had a child with ID. Their themes revolved around external (using supports, being a team) and internal (the emotional journey, my cup is half full) factors. Patterson (1991) conducted a literature review on families, disabilities and resilience and, while they noted that there were elements of resilience which are generic and common to all families, families containing a person with ID can call on unique resilience factors due to the exceptional nature of their circumstances.

Post-traumatic growth (PTG) has also been posited as a functional way families react to difficulty (Joseph & Linley, 2005). PTG can be described as positive change in response to a highly challenging life event (Tedeschi & Calhoun, 2004). Konrad (2006) highlighted unexpected elements of PTG described by mothers of children with acquired disabilities, including new-found strength, more profound beliefs about the world and renewed spirituality. Further, Zhang, Yan, Barriball, While and Liu (2013) explored PTG in mothers of pre-school children with Autism Spectrum Disorder (ASD) in China. Personal strength, appreciation for life, a new philosophy on life, relating to others and spiritual change were five aspects of PTG which they found.

The research highlighted above assumes that families containing a child with ID are inherently more stressed and are forced to "cope" with their child and adapt to the difficulties faced. In the last twenty years, research exploring the experiences or livelihoods of family members of somebody with ID has seen another shift in focus. Studies have begun to explore the experiences of family members of people with ID and found explicit positives, rather than positives from negatives. There has also been a movement towards exploring benefits and joyous experiences for families supporting a person with ID. These studies stem from a desire to highlight the subjective positive experience of people and, rather than exploring how to treat illness or minimise negatives, they aim to maximise the positives and discover the good experiences in people's lives (Seligman & Csikszentmihalyi, 2014).

This move towards exploring the good in people's lives has been termed "positive psychology". In 2000, Seligman and Csikszentmihalyi wrote a seminal piece which outlined the objective of this positive psychology movement. That is, a science of positive traits, institutions and experience which can aid in building quality of life and reducing pathology. This "science of positive traits" has been adopted in many fields within the psychology literature such as dementia and psychosis. Wolverson, Clarke and Moniz-Cook (2016) completed a systematic literature review of studies which highlighted the positive experiences and attributes of people living with dementia, finding evidence of transcendence, personal growth, strength, humour and pleasure. Within psychosis, research has focussed on several aspects of positive psychology such as happiness (Mankiewicz, Cresswell & Turner, 2013), hope (Perry, Taylor & Shaw, 2007) and spirituality (Keks & D'Souza, 2003).

In simplified terms, the timeline of research into families of people with intellectual disabilities can be termed as exploring the negatives, followed by exploring positives born from the negatives and, finally, exploring the positives in their own right. The current review aims to synthesise the positive constructs reported by family members of people with ID, that is the "positive". The reviewer was interested in a range of ID, including mild, moderate and profound as this was the first review of its kind and was intended to discover the experiences of family members across the ID spectrum. Only qualitative studies will be used as the review aims to capture the lived experiences of the people involved and their subjective experience. While there is an acceptance of the inherent challenges associated with intellectual disability for all involved, there have been countless studies exploring these challenges and the negative impacts of these. Instead, this review hopes to capitalise on the recent expansion in positive psychology literature in ID and the wider psychology field, bringing together the subjective positive experiences of family members. The aim is to synthesise the findings around positives for family members, highlighting areas for further research and possible gaps in the literature. The review also hopes to show ID in a more positive light.

Method

Search Strategy

A systematic electronic search of the literature was completed in October 2016 using PsycINFO, ERIC, MEDLINE, PsycARTICLES, Academic Search Premier and CINAHL Complete, encompassing both subject-specific and generic databases.

A comprehensive list of search terms were developed through reviewing key literature around intellectual disabilities and positive psychology to ensure all relevant articles were obtained. The search was split into three strands: family member, positive construct and intellectual disability synonym. The search terms were as follows:

- famil* OR mother* OR father* OR parent* OR sibling* OR brother* OR sister* OR relative* OR relation*
- “learning disab*” OR “learning difficult*” OR “intellectual*disab*” OR “intellectual* difficult*” OR “intellectual* impair*” OR “intellectual* disorder*” OR “mental* disab*” OR “mental* retard*” OR “mental*

handicap*” OR “mental* impair*” OR “mental* subnorm*” OR “mental* deficien*” OR “developmental* disturb*” OR “developmental* disab*” OR “develop* delay*” OR “cognitiv* disab*” OR “cognitiv* difficult*” OR “cognitiv* delay*” OR “down* syndrome” OR “learning disorder*”

- “positive* construct*” OR “personal grow*” OR hope OR awe OR inspiration* OR laugh* OR gratitude OR “post-traumatic growth” OR strength* OR spirit* OR “well-being” OR “positive* contribution” OR happ* OR satisf* OR resilienc* OR content* OR joy* OR optimis* OR “well being” OR “self-esteem”

Several limiters were also applied to the search:

- English Language
- Journal Article
- Peer-reviewed to ensure quality

There were several stages in finding the final set of papers. Firstly, the titles of each paper from the electronic search were read, with those not relevant being excluded. Second, the abstracts of those included from the title search were read, with those not relevant being excluded. Finally, the full text of the remaining articles were read and those not relevant were excluded. The reviewer also hand-searched the reference lists of the final articles to find any remaining relevant articles.

Inclusion Strategy

Papers were included if they:

- Employed a qualitative methodology, as the review seeks to understand subjective experiences.

- Found evidence of positive constructs or themes in their qualitative data, whether they intended to find positive data or not.
- Reported positive constructs stemming from the subjective account of a family member of somebody with an ID.
- Examined intellectual disability. If there was a mixed sample alongside other forms of disability, the article was included if the majority of the sample had a family member with an ID. In some studies, it was unclear whether the family member had an ID alongside another difficulty. In this case, if there was any doubt whether the sample contained people with a family member with ID, the article was excluded.
- Reported an empirical study.
- Were written in the English language.
- Were peer-reviewed.

Identification of Relevant Studies

The initial search produced 9691 articles, reduced to 8322 when duplicates were removed and an English language limiter was applied. Although a large proportion of these studies were clearly not relevant to the review, the reviewer spent ample time assessing these studies to ensure no potentially relevant studies were missed. The reviewer first assessed based on the title, followed by the abstract, excluding irrelevant studies and leaving 78 studies to be assessed by reading the full paper. Of these, 66 were found to be irrelevant, leaving 12 papers for review. However, after checking reference lists in the obtained papers, three more articles were added to the final selection of papers, leaving 15 in total.

Quality Assessment

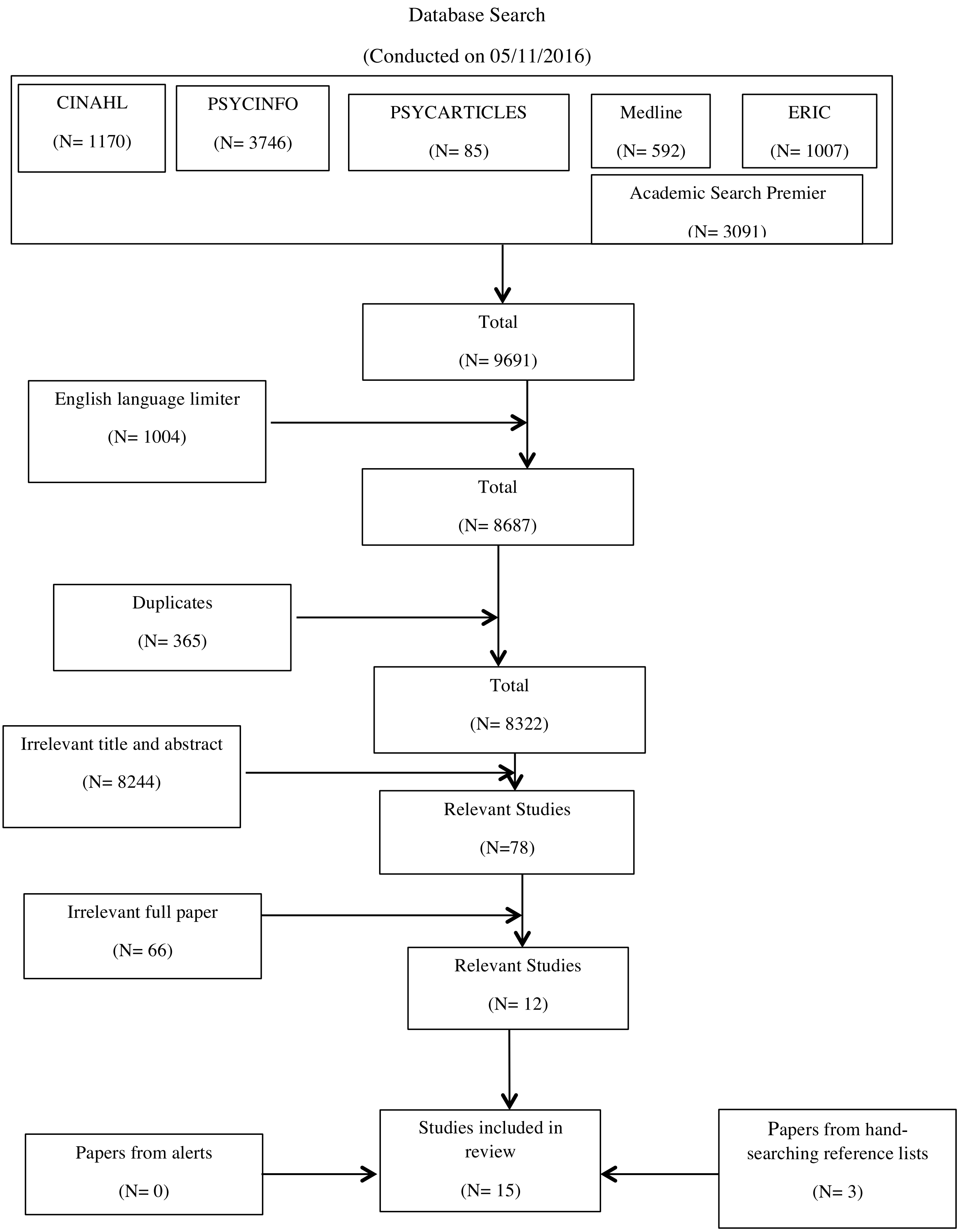
The final set of papers underwent a quality assessment by the lead researcher and a subset was also checked by a peer researcher to ensure inter-rater reliability. If there was discrepancy between the assessments, this was discussed and the lead researcher made the final decision on the quality assessment ratings.

This methodological assessment was completed using the NICE (National Institute for Health and Clinical Excellence; Methodology Checklist: Qualitative Studies, 2012) Quality Appraisal Checklist for qualitative studies, in which papers are scored: (-), where methodological quality is deemed likely to alter conclusions; (+), where methodological quality is deemed unlikely to alter conclusions or (++), where methodological quality is deemed very unlikely to alter conclusions. These assessments were completed to contextualise the findings and studies were not excluded based upon quality ratings. An overview of the quality assessment ratings are provided in Appendix C.

Data Synthesis

Data was synthesised using thematic synthesis, an approach informed by Thomas and Harden (2008). Results sections of all the studies were read and re-read in depth by the reviewer and any parts deemed relevant to positive experiences/states were extracted. This included primary quotes as well as themes created by the study authors. This information was then reinterpreted and coded before being formed into broad themes for each article. The themes for each article were then pulled together and themes across the literature were generated. These themes synthesised the data and provided an organised outline of patterns within the literature. The reviewer ceased interpretation when themes were considered to reflect the primary data which was extracted from the studies

Figure 1: Prisma Diagram showing the selection process for the studies



Results

Characteristics of Included Studies

All studies are summarised in Table 1. Included articles were largely from USA (two), UK (two), Australia (four), Canada (two) with one each from Mexico, Iran, Japan, Hong Kong and Israel. All the papers explored parents' perceptions, except one which included parents' and siblings' perspectives (Taunt & Hastings, 2002) and one other which looked at adult siblings' perceptions of their relationship with their disabled sibling (Rossetti & Hall, 2015). All the parent samples consisted largely of mothers. Two studies focussed on Down Syndrome (Pillay et al, 2012; Nelson-Goff et al, 2016) while all other studies had samples containing family members with a range of disabilities. One study explored experiences of mothers of more than one child with a disability (Kimura & Yamazaki, 2013) and one explored responses of people specifically with severely disabled siblings (Rossetti & Hall, 2015).

Twelve papers used in-depth or semi-structured interviews with one of these studies also using observation to supplement findings from the interview (Mardiros, 1989). Of the final three studies, one analysed responses to open-ended questions, one analysed narrative scripts and one analysed two focus groups. Three studies analysed the data using a constant comparative method (Stainton & Besser, 1998; Heiman, 2002; Kausar et al, 2003), four used content analysis (Taunt & Hastings, 2002; Rapanaro et al, 2008; Dyson, 2010; Nelson-Goff et al, 2016), two used a hermeneutic analysis (Kermanshahi et al, 2008; Kimura & Yamazaki, 2013) , four used a generic qualitative technique which the reviewer interpreted as basic thematic analysis and coding (Mardiros, 1989; Waggoner & Wilgosh, 1990; Crabtree, 2007; Rosetti & Hall, 2015), one explicitly used thematic analysis (Yoong & Koritsas, 2012) and one used an open coding method (Pillay et al, 2012).

Table 1: Summary of the main characteristics of the included studies

Author, date of publication, country of origin	**Aims of study**	**Participant Demographics**	**Methodological approach**	**Positives highlighted**	**Quality assessment score**
Crabtree (2007). Hong Kong	To explore several issues relating to care-giving within the family setting including: mothers' perceptions of what is understood by social inclusion of children with ID and their families and how this can be actualised.	15 mothers were interviewed, all Arab Muslims. The 17 disabled offspring, of which 9 were boys, had an age range from 4-16 (no mean given).	In-depth, open-ended interviews were conducted with the mothers, sometimes mothers were seen more than once. Qualitative methods for analysis, little information given on the technique.	Strength and resilience shown by families through acceptance of the "will of Allah" which brought apparent good fortune.	+
Dyson (2010). Canada.	To examine the unanticipated effects that children with an intellectual disability have on their families.	Two focus groups and one individual interview were conducted. One focus group contained 6 parents and one contained 7. The interview and two families were omitted from the results, leaving ten participants in total. Parents' ages ranged from 30-60 (no mean given) and their disabled children ranged from 8-16 years (M=12.1) with a range	Content analysis was used to analyse transcripts of the focus groups.	Tolerance, understanding of difference and increased maturity for NLD siblings, understanding that people with ID are gifts to be valued and increased use of social support and community resources.	+

		of disabilities.			
Heiman (2002). Israel.	To explore how resilience of parents emerges in a family with a child with a disability.	32 parents participated in this study. Parent ages ranged from 31-57 (M=41.74). All had only 1 child with special needs and had other, non-disabled children under 18. 16 of the children with special needs had ID, 9 had a physical disability and 7 had children with learning disabilities. 23 were boys, 9 were girls and they had an age range of 7-16 (M=10.92). Despite using participants with physically disabled children, this studied was included as it had majority participants with learning disabled children.	A structured interview was developed which asked about past, present and future. Qualitative methods were used analyse the data. A constant comparative method was used to code and categorise the data.	PAST, Positive reactions from others, love support; PRESENT, strengthened parental relationship, love, joy, acceptance and satisfaction and strength in successfully rearing their child; FUTURE, no positives highlighted.	+
Kausar, Jevne & Sobsey (2003). USA.	To explore and understand the experiences of hope for families of children with a significant	19 parents were interviewed using interview guide. No data on parent demographics but there	Constant comparative method of coding and categorisation used to form themes.	8 themes were composed. Experiencing care/compassion, acceptance of the	++

	developmental disability and identify circumstances which facilitate hope.	children ranged in age from 3-18 and had a wide range of intellectual disabilities.		reality of child's disability, a focus on child's abilities, positive personal transformation, unified family, sense of purpose, social support as contributor to resilience, professional attitudes.	
Kermanshahi et al (2008). Iran	To assess the lived experiences of Iranian mothers who have a child with a learning disability.	6 mothers, all housewives between the ages of 28 and 42 (M=38). Their children with a learning disability were between 6 and 12 years (M=9).	Semi-structured interviews used. A hermeneutic phenomenology was used to illuminate what it was like to live with a child with ID. Based on Van Manen (2001).	Found that religion and spirituality played a big part for the mothers as a facilitator of acceptance and resilience.	+
Kimura & Yamazaki (2013). Japan	To explore the lived experiences of mothers of multiple children with ID in Japan.	10 participants all from Tokyo area, age range 35-50 (M=41.7).	10 semi-structured interviews were completed and analysed using IPA and three superordinate themes were found as well as 7 subordinate themes.	Confidence to overcome difficulty due to past experience, sense of safety in others sharing the burden, grateful for unique child.	++
Mardiros (1989). Mexico	To examine the response of Mexican-	33 parents participated, representing 25	Observations of interactions between	Acceptance of child and disability	+

	American parents to their severely disabled child.	families. 10 fathers, 23 mothers. Age range 21-55 (M=37).	parents and child and semi-structured interviews were conducted. Follow-up telephone interviews were conducted 2-4 weeks after the last interview. No mention of type of analysis.	identified as an awareness of the child's capabilities as well as grief followed by eventual acceptance. Disability served as creative catalyst, expanding perspectives on life. Personal growth occurred in assertiveness, creativity etc.	
Nelson- Goff et al (2016). USA	To compare parents of children with Down's Syndrome across the lifespan of their child on different areas of functioning quantitatively and qualitatively assess their opinion of their child's diagnosis.	445 usable responses, 216 with a child under 5, 132 with a child between 5 and 11 and 50 with a child between 11 and 18 as well as 47 with a child over 18. Average age of respondents was 49.91, no gender differences reported.	Mixed methods. Quantitative measures used but not reported here. Qualitative data collected by asking open-ended question at the end of the quantitative forms. Question was coded using content analysis	Having a positive attitude, acceptance of the diagnosis and how their child is, spiritual growth, seeing the child as a blessing, personal growth and becoming a better person.	++
Pillay et all (2012). Australia.	To describe the experience of parenting for mothers with a child with Down Syndrome	8 mothers of children aged between 7 and 12 with Down Syndrome participated in an in-	In-depth interviews were completed and an open coding method was used to analyse the data.	5 core themes. The journey begins, birth, diagnosis and acceptance; raising	++

	and to explore the role of spirituality and religion in this experience.	depth interview.		the child, mix between pride and grief and advocacy for their child; significant stressors; sources of support, spirituality, family support, personal coping styles, inspirational resources, religion; outcome, included increased family unity, increased maturity for siblings, more grateful and relaxed.	
Rapanaro, Bartu & Lee (2008). Australia	Positive outcomes (perceived benefits) associated with the challenges for parents during the period of transition from childhood to adulthood for their disabled child. The study also reported on negative outcomes from this period.	119 parents (90% female) completed the questionnaire, all of whom had a son/daughter aged 16-21 with ID.	Parents were asked to event/situation where they had experienced unpleasant feelings, feelings of being unable to do things as expected. They were then asked to describe positive/negatives from the event and general positives/negatives of caring for their child. The results were analysed using qualitative content	Personal growth, improvement in social support, enhanced personal growth of child, sense of pride, absence of certain care demands (e.g. dressing, bathing, entertaining).	++

			analysis and categories were created.		
Rosetti and Hall (2015). Canada.	To test the efficacy of the The Quality of Life Survey and to gather data around quality of life for families containing a child with an intellectual disability	Parents of 34 families. Fathers age range 42-73 (M=53.93), mothers age range 37-74 (M=53.64). Child with disability age range 10-38 (M=21.74) and they had a wide range of disabilities	Participants were interviewed using questions from The Quality of Life Survey. Qualitative data was organised.	Spiritual and cultural beliefs, family relationships and careers contributed to quality of life and families generally reported high life satisfaction.	++
Stainton & Besser (1998). UK	To provide qualitative data which suggests positive impacts of people with a learning disability on their families and supports the existing literature in this area.	Group interviews had 6 fathers and 9 mothers fom 9 different family units. Age range was 25-70 (M=50).	Two semi-structured group interviews took place and two single family interviews. Transcripts were analysed using the constant comparative method and nine core themes were identified.	Nine core themes identified: Source of joy, increased sense of purpose, expanded personal/social involvement, increased spirituality, source of family unity, increased tolerance, personal growth, positive impacts on others/community.	++
Taunt & Hastings (2002). UK	To explore the perceptions of parents of the impact of their	Two samples. First has 14 parents from 10 families. Parents from	Sample 1 participated in semi-structured interviews. Sample 2 answered open-	Found 6 categories from content analysis, positive	+

	disabled child on siblings and the extended family, whether parents report positive views about the future as well as past and present and the explicit impact their disabled child has had on the parents themselves.	the same family were interviewed together. Two siblings also completed interviews. Sample 2 was 33 parents who responded to internet survey.	ended questions in the survey. This study used a quantitative/objectivist approach but produced categories from content analysis.	impact of the child, changed perspective on life, increased sensitivity, support from other families, opportunities to learn, improved family dynamics, increased confidence, strengthened religious faith.	
Waggoner and Wilgosh (1990). USA	To share the experiences and concerns of parents of children with intellectual disabilities.	Parents from 8 families, 4 with both parents, 4 with just the mothers. No ages for parents given. 6 families had one child with ID and 2 had more than one. The children ranged in age from 9-18 and 9 of the 11 children were boys.	No detail on qualitative analysis but transcripts were "examined for themes" following in-depth interviews.	Seven themes were outlined, only one relevant to the current review. "The effects on the family" where parents highlighted added strength to the family and increased maturity for siblings.	-
Yoong & Koritsas (2012). Australia.	To explore the impact of caring for an adult with ID on the quality of life of parents.	12 parents (10 women, 2 men) with age range 55-77 (M=66.4). 11 cared for one offspring with ID while one cared for two.	The parents participated in interviews. 10 interviews were conducted as married couples were interviewed together. Data was analysed using	Found positive effects on relationships and support, leisure participation, personal	++

thematic analysis	satisfaction.

Methodological Quality

The quality ratings of each study are provided in Table 4 (Appendix C). One paper scored the lowest rating (-), fulfilling none or few of the criteria, seven achieved (+), where most criteria were fulfilled so it is unlikely to affect the study's conclusions, and seven achieved (++), where all or most criteria were fulfilled.

Waggoner and Wilgosh (1990) was the only article to score (-). This was due to inadequate and unclear reporting across the study, including an unclear design and theoretical approach, limited information regarding ethics, and inadequate reporting of the analysis.

Of the remaining studies, ten provided sufficient information regarding ethics, whereas five studies lacked detail relative to this. Six were deemed to have completed very good analysis with reliable methods, convincing findings and plausible conclusions, one had inadequate analysis, with a lack of analytic rigour and poorly reported findings, four were deemed to have completed analysis which provided plausible findings but lacked in rigour or were under-reported and four were deemed to have completed good analysis which provided plausible conclusions but did not achieve very good due to limited reporting or a lack of rigour. The majority of studies (12) were clear about researcher and participant context and used reliable data collection methods. Of those that were not, the research context of two studies was unclear, but the rationale for conducting the study was clear (Taunt & Hastings, 2002; Kermanshahi et al, 2008). One other study clearly outlined the research context, but the rationale for the study remained unclear (Waggoner & Wilgosh, 1990).

Thirteen studies were adjudged to have appropriate data collection methods, whereas two studies inadequately reported this (Crabtree, 2007; Rapanaro et al, 2008). Eleven studies had a defensible rationale for their research design. Two were adjudged to have an appropriate design, but their justification for it was unclear or unreported (Heiman, 2002; Crabtree, 2007), one did not clearly explain their design (Waggoner & Wilgosh, 1990), and one had both an unclear rationale and design (Mardiros, 1989). A qualitative approach was appropriate for all the studies but Mardiros (1989) did not report a clear objective for the study, making it difficult to assess the appropriateness of a qualitative design. Overall, the studies had sound methodological quality, and the findings were unlikely to be affected by the limitations outlined in all but one study (Waggoner & Wilgosh, 1990).

Results

Table 2: Overview of themes and supporting studies.

Superordinate Theme	Subtheme	Supporting Studies
Growth	Personal Growth	Stainton & Besser, 1998; Kausar, Jevne & Sobsey, 2003; Dyson, 2010; Crabtree, 2007; Rapanaro, Bartu & Lee, 2008; Pillay, Girdler, Collins & Leonard, 2008; Waggoner & Wilgosh, 1990; Taunt & Hastings, 2002; Kimura & Yamazaki, 2013.
	Change in Perspective	Stainton & Besser, 1998; Kausar et al, 2003; Rapanaro et al, 2008; Pillay et al, 2008; Yoong & Koritsas, 2012; Taunt & Hastings, 2002; Dyson, 2010; Kimura & Yamazaki, 2013.
	Family Strength	Mardiros, 1989; Stainton & Besser, 1998; Heiman, 2002; Kausar et al, 2003; Kermanshahi et al, 2008; Pillay et al, 2008; Rapanaro et al, 2008.
Joy	Pride	Stainton & Besser, 1998; Crabtree, 2007; Rapanaro et al, 2008; Pillay et al, 2008;

		Rosetti & Hall, 2015; Nelson-Goff et al, 2016; Yoong & Koritsas, 2012.
	Person as a Treasure	Kausar et al, 2003; Rapanaro et al, 2008; Rosetti & Hall, 2015; Kermanshahi et al, 2008; Stainton & Besser, 1998; Heiman, 2002, Nelson-Goff et al, 2016; Kimura & Yamazaki, 2013; Yoong & Koritsas, 2012; Dyson, 2010.
Developing ways to cope	Spirituality	Crabtree, 2007; Kausar et al, 2003; Kermanshahi et al, 2008; Mardiros, 1989; Taunt & Hastings, 2002; Stainton & Besser, 1998; Nelson-Goff et al, 2016; Pillay et al, 2008.
	Acceptance	Crabtree, 2007; Kausar et al, 2003; Kermanshahi et al, 2008; Kimura & Yamazaki, 2013; Heiman, 2002; Nelson-Goff et al, 2016; Pillay et al, 2008.
	Strength	Rapanaro et al, 2008, Stainton & Besser, 1998; Pillay et al, 2008; Kimura & Yamazaki, 2013; Crabtree, 2007; Kermanshahi et al, 2008; Nelson-Goff et al, 2016; Taunt & Hastings, 2002; Waggoner & Wilgosh, 1990; Rosetti & Hall, 2015; Yoong & Koritsas, 2012; Kausar et al (2003)
	Developing Support Systems	Kimura & Yamazaki, 2013; Taunt & Hastings, 2002; Waggoner & Wilgosh, 1990; Rapanaro et al, 2008; Stainton & Besser, 1998; Yoong & Koritsas, 2012; Dyson, 2010.

Growth

The first superordinate theme describes the aspect of positive change for participants across the literature, including personal characteristics, changes in values and stronger ties with family and loved ones. These three areas all involve change over time from a subjectively less desirable state to a more desirable state.

Personal Growth

Many of the studies in this review report elements of positive, personal change for participants. Studies talked about tolerance and understanding of difference (Stainton & Besser, 1998; Kausar, Jevne & Sobsey, 2003; Dyson, 2010), becoming more understanding and compassionate (Kausar et al, 2003; Crabtree, 2007; Rapanaro, Bartu & Lee, 2008; Pillay, Girdler, Collins & Leonard, 2008), an increase in maturity, particularly in siblings (Waggoner & Wilgosh, 1990; Stainton & Besser, 1998; Taunt & Hastings, 2002; Pillay et al, 2008; Dyson, 2010) and being more assertive and self-confident (Stainton & Besser, 1998; Rapanaro et al, 2008; Kimura & Yamazaki, 2013):

It's probably the biggest impact that these children had on our lives is that we go beyond whatever biases you may have picked up when you were a kid.

(From the theme "Source of increased tolerance and understanding": Stainton & Besser, 1998: Page 65)

The kids have gotten values in a lot of ways well beyond their years…

(From the theme "the effects on the family": Waggoner & Wilgosh, 1990, page 98)

.. and will not take 'no' for an answer anymore.

(From the category "enhanced personal resources": Rapanaro et al, 2008: Page 41)

What emerges from the literature is that people who experience caring for or growing up alongside somebody with an ID become accustomed to difference and are more tolerant of difference in other people, as well as exhibiting enhanced maturity due to the greater responsibility they take on. Participants across the literature also described fighting for resources and support, and how this has caused them to become more assertive, as one parent said to their child “Look at what you have made of us. You made us door openers" And we're getting really good at it” (Stainton & Besser, 1998, page 65). Another participant described how, “We have to fight for things” (Heiman, 2002, page 165).

Change in Perspective

Across the literature, participants describe how their experience of their disabled relative had, for whatever reason, altered their outlook on life. In particular, this meant finding value in different things and being able to appreciate life more (Stainton & Besser, 1998; Kausar et al, 2003; Rapanaro et al, 2008; Pillay et al, 2008; Yoong & Koritsas, 2012).

(it) helped me to realise what is really important in life

(From the category “personal growth/enhanced resources”: Rapanaro et al, 2008, page 44).

It makes you realise what's important in life

(From the theme “increased sense of purpose and priorities”: Stainton & Besser, 1998, page 62).

Participants also reported enjoying opportunities to learn new things (Stainton & Besser, 1998; Taunt & Hastings, 2002), as well as seeing things in a different way (Kimura & Yamazaki, 2013). As one participant said, “But my children are accepting of everybody, whether they are in a wheelchair or if they're Down syndrome or whatever” (Dyson, 2010, page 51) and another stated, “Having our daughter has made us more caring adults and less worried about material things” (Rapanaro et al, 2008, page 44).

Family strength

The final subtheme within growth was family strength. The literature describes feelings of increased strength and closeness in the spousal relationship (Mardiros, 1989; Stainton & Besser, 1998; Heiman, 2002; Kausar et al, 2003; Kermanshahi et al, 2008; Pillay et al, 2008), as well as increased strength and closeness in the nuclear and extended family (Mardiros, 1989; Stainton & Besser, 1998; Kausar et al, 2003; Pillay et al, 2008; Rapanaro et al, 2008).

I think that it's made my husband and myself closer

(From the theme “Unified Family”: Kausar et al, 2003, page 41)

I mean, I had a strong marriage going into the child and it’s made us grow as a couple

(From the theme “Source of Family Unity”: Stainton & Besser, 1998, page 64)

He’s brought us closer and both our daughters are taking part in the process

(From the theme “Source of Family Unity”: Stainton & Besser, 1998, page 64)

The overarching message in this theme is one of relationships becoming stronger and more meaningful to participants across the literature as they grow and change through their experience.

Joy

The next superordinate theme was joy, and this was extremely prevalent across the literature. It describes the pure joy of the disabled person and the happy and positive moments which participants have experienced in their presence.

Pride

Across the literature, the studies reported strong elements of pride in the disabled family member. This largely involved taking pleasure in the person’s achievements and focussing on their strengths (Stainton & Besser, 1998; Crabtree, 2007; Rapanaro et al, 2008; Pillay et al, 2008; Rosetti & Hall, 2015; Nelson-Goff et al, 2016), but there were also examples of family members feeling pride in themselves for the job they have done as carers (Yoong & Koritsas, 2012; Nelson-Goff et al, 2016).

…I am so proud of his accomplishments.

(From the theme “Guilt”: Rosetti & Hall, 2015, page 128)

She has an associate's degree from a community college. She has been competitively employed full time for the past 7 years and has relied on natural supports in her job. Her employment evaluations and reviews have been outstanding and she is a valued employee.

(From the discussion of "Child's accomplishments": Nelson-Goff et al, 2016, page 1141)

If you give her a big meal and she's happy, and you bathe her and she's all fresh, and clean, and happy, then you're proud of that.

(From the theme "Personal Satisfaction": Yoong & Koritsas, 2012, page 613)

Person as a Treasure

This subtheme was significant across the literature and encompassed viewing the disabled person as a blessing/treasure, seeing them as a source of comfort/companionship, making joyous memories with them and taking pleasure from them (Kausar et al, 2003; Rapanaro et al, 2008; Rosetti & Hall, 2015; Kermanshahi et al, 2008; Stainton & Besser, 1998; Heiman, 2002, Nelson-Goff et al, 2016; Kimura & Yamazaki, 2013; Yoong & Koritsas, 2012; Dyson, 2010).

Just seeing her smile can make my day a million times better

(From the theme "Joy": Rosetti & Hall, 2015, page 128)

They are cute. Well, any child must be cute for his or her parents, but there are parts that are difficult and that are dear and lovable because of the disability. Smiles, gestures, silliness . . . everything is cute

(From the theme "Feeling Grateful for Children with Disabilities Possessing Unique Characteristics": Kimura & Yamazaki, 2013, page 1315).

Miss A is my little mate, wherever I am, she will come out and help me, or try to, in her way.

(From the theme "Relationships and Support": Yoong & Koritsas, 2012, page 612)

Developing ways to Cope

This was the final superordinate theme. Largely this involved overcoming difficulties and learning to cope with the hardships which are inherent within disability. The four subthemes reflect this as they are all mechanisms for coping and things which may develop in response to a difficult experience.

Spirituality

Spirituality was mentioned across the literature in terms of religious faith, but also in terms of non-specific spirituality where participants alluded to something greater than themselves but not specifically religion. Within the literature, there was mention of the child being a test for parents and the family being specially selected by God (Crabtree, 2007; Kausar et al, 2003; Kermanshahi et al, 2008; Mardiros, 1989), as well as strengthened religious faith and enhanced spirituality (Taunt & Hastings, 2002; Crabtree, 2007; Stainton & Besser, 1998; Nelson-Goff et al, 2016; Pillay et al, 2008).

Whatever happens, it is the will of God. It has been my fate. I've accepted the birth of my child easily and believe that it has been God's wish to test me

(From the theme "Being in the Midst of Life and Death": Kermanshahi et al, 2008, page 320)

I feel that children are gifts and God doesn't make mistakes

(From the theme "Spiritual Beliefs": Kausar et al, 2003, page 42)

It can be so joyous in its simplicity and that for me has made me more spiritual

(From the theme "Source of Increased Spirituality: Stainton & Besser, 1998, page 63)

The overarching concept reported by studies was one of a higher power and there being a plan for participants. This quote in Nelson-Goff et al (2016, page 1138) was typical "I know there are going to be challenges, so I don't want to sound naïve. But I also know things happen for a reason and with many things in life, there are challenges and obstacles to overcome". This participant uses this "reason" as a way to remain resilient and overcome difficulty.

Acceptance

This subtheme involved the process of participants accepting the situation, moving forwards and coping through this acceptance. It also encompassed aspects of gratitude and hope as well as positivity and optimism (Crabtree, 2007; Kausar et al, 2003; Kermanshahi et al, 2008; Kimura & Yamazaki, 2013; Heiman, 2002; Nelson-Goff et al, 2016; Pillay et al, 2008).

I feel like I have moved past any hard feelings about it. I cannot imagine life without him. He is a wonderful son. I do not care if he has down syndrome.

(From the discussion of "Acceptance": Nelson-Goff et al, 2016, page 1139)

I guess it's finding contentment in where she's at and also seeing the beauty in her.

(From the theme "The Journey Begins": Pillay et al, 2008, page 1504)

Many studies reported parents entering a process where they originally experience shock and grief but, through time, begin to recognise there are positives as well as coming to terms with the difficulties they face, allowing them to experience the joy, pride, growth which is highlighted in previous themes.

Strength

Again, this subtheme was prevalent in many studies and largely involved learning to cope (Rapanaro et al, 2008, Stainton & Besser, 1998; Pillay et al, 2008), drawing on previous difficult experiences (Kimura & Yamazaki, 2013; Crabtree, 2007; Kermanshahi et al, 2008; Nelson-Goff et al, 2016), having optimism for the future (Taunt & Hastings, 2002) and being strong for the person with ID (Waggoner & Wilgosh, 1990; Rosetti & Hall, 2015; Yoong & Koritsas, 2012).

It was necessary for me to advocate on his behalf with another service provider to retain level of funding…

(From the theme "Service Provider Issues": Rapanaro et al, 2008, page 37)

My current attitude about my child's diagnosis is extremely positive. It's the feeling of waking up on Christmas morning when you're a child, multiplied by a million.

(From the discussion on "Having a Positive Attitude": Nelson-Goff et al, 2016, page 1138)

So if the second child doesn't have a disability, then it's a good thing, but even if the second has a disability, it works out because you have experience from the first

(From the theme: "Drawing on Difficult Experiences": Kimura & Yamazaki, 2013, page 1314)

Participants described the need to be strong in order to cope with difficulty but also to ensure they could advocate for the person with a disability, as this participant in Kausar et al (2003, page 42) demonstrates, "Maybe there was another meaning behind having a child with a disability, maybe it was so that later in life I would be a stronger advocate for other people as well as my daughter".

Developing Support Systems

This subtheme was present across many of the studies in this review and using the support of others was often cited as a means of coping with difficulties. Studies also reported that many participants felt a sharp rise in the increase of opportunities to expand their social network due to experiences associated with their disabled family member (Kimura & Yamazaki, 2013; Taunt & Hastings, 2002; Waggoner & Wilgosh, 1990; Rapanaro et al, 2008; Stainton & Besser, 1998; Yoong & Koritsas, 2012; Dyson, 2010).

The parents' association for children with disabilities has helped me learn a great deal, and I have come to think that it can work out.

(From the theme "Recognising those who Share the Burden": Kimura & Yamazaki, 2013, page 1315)

[it] allows me to meet many great people I otherwise would not meet

(From the category "Enhanced Social Network": Rapanaro et al, 2008, page 44)

"I'm pretty lucky because I have resources. I have research skills and my best friend's a learning assistant teacher in town"

(From the theme: "Effective Coping: Dyson, 2010, page 52).

From the literature, it is clear that the person with a disability increased the opportunities for family members to increase their social network and that this improved social network then aided in coping with the inherent difficulties in their lives.

Discussion

This review aimed to highlight and synthesise the positive aspects and experiences for families containing a person with ID, grounded in a positive psychology approach (Seligman & Csikszentmihalyi, 2000). The positives for family members remain under-researched, with the dominant narrative in the literature base being persistently negative (Davys, Mitchell & Haigh, 2011). However, this review brings together the literature that does exist surrounding the positives families' experience of having a relative with ID.

There is considerable evidence in the literature for development of the self and growth following trauma or difficulty (Schaefer, 1992) with studies focussing on resilience in the face of challenges (Gardner & Harmon, 2002) and PTG following trauma (Konrad, 2006). However, what has emerged in this review is that growth does not necessarily occur from the challenge of having a person with ID in the family, but occurs due to the unique and special experiences and circumstances which family members are exposed to. Family members develop compassion, understanding, maturity and self-confidence and learn the value of life through these experiences. This fits with theory from other areas such as the dementia literature where gerotranscendence has been posited as an explanation for "ageing well", not simply responding to the challenges of old age (Wolverson, Clarke & Moniz-Cook, 2016). The finding in this review also fits with early psychological theory, namely Maslow's (1943) Hierarchy of needs. Maslow discusses five steps in his hierarchy, ending with self-actualisation which describes personal growth and development engendered by fulfilment and meaning in life. This is consistent with the literature in this review, with personal growth developing and a change in what participants value and hold dear through having a sibling with ID. The findings in this review suggest a change in perspective and recognising what is truly important in life can be achieved or accelerated through having a sibling with ID. This change in perspective then allows the development of personal growth. There is a need for this theoretical basis to be further explored in future research.

The third subtheme of 'family strength' could be split into two areas: unity and strength in the spousal relationship and unity among the nuclear and extended family. Across the literature, participants discussed how they had been brought closer by the birth of their relative with ID. Of particular interest is the report of the strengthening of the spousal relationship. Within ID, there has been a prevailing belief that divorce and separation rates are higher among parents of children with ID but the empirical evidence which suggests this is the case is largely of poor methodological quality (Freedman, Kalb, Zablotsky & Stuart, 2012). In fact, there is significant evidence to suggest that divorce rates among parents of children with ID are no higher than parents of non-disabled children (Baeza-Velasco, Michelon, Rattaz, Pernon & Baghdadli, 2013; Namkung, Song, Greenberg, Mailick & Floyd, 2015) and, indeed, some research suggests divorce rates are lower (Urbano & Hodapp, 2007). The findings in this review would support reports that spousal relationships are in fact strengthened by the birth of a child with ID.

The second superordinate theme was joy, encompassing two subordinate themes. These were 'pride', recognising and celebrating the disabled relative's achievements, and 'the relative as a treasure', someone who brings joy and happiness to non-disabled relatives' lives. Contextually to the wider ID literature, this finding is unusual. Largely, the literature has discussed the burdensome and stressful nature of people with ID on their immediate family. For example, Wikler (1981) discussed the persistent grief which parents feel throughout parenthood as their child with ID continually fails to meet their expectations. Moreover, Kazak and Marvin (1984) found that families containing a child with ID exhibited more stress. Further, there is evidence that wider society views people with ID as burdensome (Office for National Statistics, 2014). In this review however, the concepts of the person as a 'treasure' and a 'joy' highlight the positive impact which people with ID can have on family members, not highlighted in the literature elsewhere.

As well as the feelings of pride in the accomplishments of the disabled person, there was also evidence that family members took pride in their own achievements as carers. Parallels can be drawn here with other areas. Brooks, Farquharson, Burnell and Charlesworth (2014) found carers of people with dementia expressed pride in their job as a carer and were proud to tell others what they do. Further, Winkler, Bedford, Northcott and Hilari (2014) described the pride which carers of people with aphasia feel in both their own achievements and the achievements of the person they care for. Thus, this review has found pride associated with a caring role extends to family members of people with ID.

The final higher order theme was resilience. This encompassed four lower order themes which were all deemed to be positives and assets which had developed to help participants cope with hardships and challenges.

The first lower order theme was spirituality. Notably, spirituality was more prevalent in studies completed in non-western countries, with studies completed in Mexico (one) and Asia (four) more likely to have results relating to spirituality and religion. However, there was significant evidence of spirituality as a source of resilience in several studies carried out in Western countries (six). Often, this spirituality manifested as religion and participants spoke about a reliance on God and Their plan for them. This often seemed to provide participants with strength to overcome any challenge. Previous research has hypothesised that religion can have a large impact on the outcomes for people undergoing challenges and difficulty. Park and Folkman (1997) explain how religion provides a form of resilience as people change their perception of the situation to fit their religious beliefs. Therefore, when a challenging life event occurs, for example the birth of a disabled child, parents are able to alter their perspective and view this as a challenge from God or see themselves as specially selected by God. While not all participants in the reviewed studies talked about spirituality in terms of religion, there was often reference to a higher power which can be relied upon to have a plan or provide support.

Therefore, this review has provided evidence that spirituality can, and does, provide an important element of support for families of people with ID.

A further subtheme was “developing support systems”, as several studies in this review noted the increased opportunities participants discussed through having a person with ID in the family. Often, families expanded their social network out of necessity, as a way to gain support but families also discussed inadvertently meeting new people and making new friends through contact with services. The level of support they then gained helped them to cope with any challenges they faced. This fits with two prominent theories of coping through social contact described by Cohen and Willis (1985). The first, the main effects hypothesis, suggests that integration into a group provides people with stability, positive affect and increased self-esteem and allows them to avoid stress through negative experience. The second is the buffering hypothesis which posits that a potentially stressful event does not cause stress because of the knowledge that there is immediate support when a challenge arises, increasing confidence to be able to cope, and that there is emotional support after the event to reduce the stress reaction of the body. In this review, studies noted the supportive effect which increased social contact had for families, both as a way of reducing the onset of stressful events, through advice from other families, ongoing emotional support, and reducing the impact of stressful events, through immediate practical support and emotional support after a stressful event.

The two subthemes ‘spirituality’ and ‘developing support systems’ could be deemed developing ways to cope through external means. The two other subthemes within ‘developing ways to cope’, ‘strength’ and ‘acceptance’, could be deemed coping through internal means and resources. Across the literature, there are reports of participants developing strength of character through learning to cope with difficult experiences, allowing them to be optimistic about their ability to cope with future challenges. There was also significant reports of the *need* to be strong in order to obtain the necessary services and also to ensure their disabled relative was treated fairly and given adequate opportunities to prosper.

This strength has been discussed previously in other literature in terms of resilience and there appears to be a significant interplay between this strength and resilience and acceptance of the child with ID. As discussed previously in this review, the birth of a disabled child is often a shocking and difficult experience for parents (Solnit & Stark, 1961; Dale, 1996). However, despite the shock and reported grief for a ‘normal child’, as well as difficulty for siblings and other family members, families are able to adapt and, based on the findings of this review, prosper from and enjoy the experience of having a sibling with ID. Previous research has likened the reaction to a child with ID to the stages of grief with Fraser, Sines and Kerr (1998) describing five stages of acceptance: shock, denial, sadness, adaptation and reorganisation. The stages described here are consistent with findings in this review, where the literature discusses participants’ use of gratitude, hope and optimism in helping them accept and move forward, developing strength and confidence in meeting any challenge and ensuring their relative receives appropriate services and treatment.

Limitations

A significant limitation which has been discussed in several previous literature reviews is whether the findings from studies with differing epistemological stances can be compared and synthesised (Walsh & Downe, 2005). While these studies were all qualitative, there is a mix of different designs and epistemologies and it must be accepted that this may reduce the validity of the review findings.

Further, Thomas and Harden (2008) highlight that thematic synthesis incurs an extra layer of interpretation on the part of the reviewer, which takes the findings further from the original participants’ experiences. The reviewer aimed to stay as true to the original data as possible to minimise this possibility.

This review did not include non-English language studies. This represents an element of publication bias as there are potentially studies written in other languages which would have added to the review and increased the richness of the findings.

Further, the studies included largely relied on a sample of women from Western countries, suggesting the perspectives of the participants represent a narrow demographic. Moreover, while the methodological quality of the studies was generally good, there were limitations, particularly around ethics for several studies, and, therefore, this review must be interpreted with this in mind.

A final limitation is the interpretative nature of the review. The review aimed to synthesise positives for family members and, while the reviewer believes the results are valid and representative of participants perspectives, some of the positives stated were not necessarily interpreted as positives in the original article, and there may be an element of interpretation bias on the part of the reviewer.

Implications

Contrary to the large majority of literature surrounding ID, this review has found significant evidence of positives for family members. The hope is that this review provides a starting point for future research to expand on the themes which are discussed within it and will also provide hope and optimism for family members.

A significant finding in this review is the ways participants developed and fostered strength and ways of coping. This review provides evidence that developing good social support increases the ability to cope and reduces the likelihood of stress and challenge. Support groups and social groups for family members of people with ID may be beneficial in maintaining mental and physical health while sharing ideas and helping to develop internal strength and acceptance. Family members reading this may recognise in themselves the internal acceptance and strength reported here but, if not, may be heartened to note that many relatives develop this with time and experience.

While this review noted that participants reported challenge and difficulty and were innovative in developing ways to cope with this, this review also noted explicit positives. Participants discussed unique experiences which were joyful and caused great pleasure. These joyous experiences combined with the challenges and difficulty caused the participant to develop as people into compassionate, mature adults. This finding is interesting in that it suggests participants not only cope in spite of their difficulties but develop and live well. The review hopes this finding may help engender a further shift away from the focus on the negative in the ID literature towards a focus on positive, fulfilling experiences for family members.

Conclusion

Earlier in this review, it was noted that research into families of people with ID had begun with researching the negative, followed by researching the positive from the negative and, finally, to researching the positives in their own right. This review has found evidence in the literature base of both the positive resulting from the negative and the positive. The first two superordinate themes show evidence of the positives for families, whether that be developing their personal attributes, learning to value life or experiencing the pure joy and pride of their disabled relative. The final superordinate theme, ‘developing ways to cope’, discusses the positive which has developed from the negative. The challenges and difficult experiences which family members undertake cause them to adapt and develop coping strategies, whether that be developing acceptance and strength, confidence in more external concepts such as religion or spirituality or learning to use the support of others to cope. The implications of these findings for families are that they can develop strength resilience and benefit from negative experiences but also highlight the many joyous and unique circumstances which family members of people with ID experience and benefit from.

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Part Two: Empirical Paper

The lived experience of personal growth for adult siblings of people with an intellectual disability

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This paper is written in the format ready for submission to the *Journal of Applied Research in Intellectual Disabilities* (see Appendix A for submission guidelines).

Word count: 6602

Abstract

Introduction

Research within intellectual disability has largely focussed on the negative aspects, with the difficulties experienced by parents and siblings a particular focus. There has been a recent expansion in research surrounding positives for family members, including personal growth. This qualitative study aimed to explore adult siblings' lived experiences of personal growth.

Method

Semi-structured interviews were completed with seven participants and Interpretative Phenomenological Analysis was used to analyse the data.

Results

The analysis generated three superordinate themes 'Developing Strength', 'Learning Opportunities' and 'Family Closeness'. 'Developing Strength' encompassed participants learning acceptance, resilience and being an advocate for their disabled sibling. 'Learning Opportunities' captured participants' experience of learning values and skills and gaining a unique insight and understanding of others. 'Family closeness' describes participants' experience of feeling closer with their nuclear family and disabled sibling as well as feeling pride in the accomplishments of their disabled sibling.

Conclusions

The findings suggest siblings develop acceptance and resilience which serve as a bedrock for them to thrive and build skills and grow.

Introduction

In the past, research in intellectual disability (ID) has been heavily focussed on the negative aspects for all those involved. There has been significant literature focussing on the difficulties faced by parents. The Department of Health (2001) define ID as a significantly reduced ability to learn new skills alongside difficulties with independent coping with these problems beginning before the age of 18. Dyson (1996) found that the adaptability of families containing an intellectually disabled child was much lower and parental stress in the household was significantly higher. Similarly, Heiman (2002), interviewed parents of a child with an ID and found that many expressed dissatisfaction and frustration in their life. Further, Oelofson and Richardson (2006) compared parents of children with a developmental disability and parents of non-disabled children and found the former expressed greater parenting stress, a lower sense of coherence and mothers exhibited poorer physical health.

Equally, there is significant research highlighting the negative impact intellectually disabled children can have on their non-ID siblings. For example, Hartling et al (2014) noted the often deleterious and damaging effect ID can have on the non-ID sibling. Further, Bagenholm and Gillberg (1991) compared non-ID siblings of children with an ID, autism or no disability. Siblings of children with ID and autism felt lonely more often, had more difficulties with peers and were more likely to regard their sibling as a burden. Similarly, Benderix and Sivberg (2007) completed a content analysis of interviews completed with 14 siblings of children with ID and autism which revealed seven themes which led them to the conclusion that a child with an intellectually disabled sibling experiences extremely stressful life conditions. These themes were: precocious responsibility; feeling sorry; exposure to frightening behaviour; empathetic feelings; hoping that a group home will be a relief and physical violence made siblings feel unsafe and anxious and relationships with friends were affected negatively.

Hence, the literature on the impact on families containing a person with an ID has focussed predominantly on the negative aspects of this experience for both parents and siblings alike. However, this slant in the literature towards the negative and pathological has been widely noted throughout the psychology literature, not only in the domain of ID. There are examples across the dementia literature (Etters, Goodall & Harrison, 2008), the psychosis literature (Ewertzon, Cronqvist, Lutzen & Andershed, 2012) and other areas such as the transgender literature (Lombardi, Wilchins, Priesing & Malouf, 2002) and the HIV/AIDS literature (Mahajan et al, 2008). In recent times, an alternative outlook has been posited as a way of conducting research, that of positive psychology. Seligman and Csikszentmihalyi (2000) described positive psychology as a science which focusses on positive subjective experience, positive individual traits and positive institutions which can improve quality of life and prevent the pathologies and difficulties of life from becoming meaningless and barren. The science aims to explore positive traits such as wisdom, spirituality and growth in order to understand their effects as well as help them flourish.

This positive outlook has begun to expand across the psychology literature where previously the focus within these areas had been on the negatives. For example, dementia has previously been perceived in a negative light, with dementia patients largely side-lined and portrayed as lost, with a focus on the struggles of those around them, leaving them with a struggle for agency in their own life and care (Herskovitz, 1995; Kontos, 2005). However, in recent times, application of the positive psychology framework has begun to highlight positive constructs across the area. Wolverson, Clarke and Moniz-Cook (2010) examined hope in dementia using semi-structured interviews to obtain the views, experiences and understanding of people living with dementia and how re-appraisal of their understanding fostered hope. Further, Leipold, Schacke and Zank (2008) found that caregivers of those with dementia had increased personal growth over twenty-seven months. They used the term “cognitive maturity” and found that personal growth positively correlated with the number of caregiving tasks they were required to complete.

Positive psychology has also taken hold within the ID literature. It seems that positives have always been present, they have just not been the focus of research. For example, while Heiman (2002), mentioned earlier, reported parent’s dissatisfaction and frustration, they also noted parents’ optimism and positivity. Graff et al (2012) interviewed adolescent siblings of children with Down Syndrome and found that the participants emphasised the positives far more than the negatives. Other studies noted potential positives but this was often reported in terms of an absence of the negatives as opposed to positives. For example, McHale and Gamble (1989) noted that children with disabled siblings had no particular adjustment problems compared to children with typically developing siblings. Also, McHale, Sloan and Simeonsson (1986) noted that children with autistic or disabled siblings did not differ on any self-report scale when compared to children with non-disabled siblings.

Now, however, research is beginning to study the positives and highlight the benefits associated with ID, rather than just viewing these as an absence of negatives. For example, Taunt and Hastings (2002) asked parents what positive impact their intellectually disabled child has had on their family. The parents reported a range of positives for themselves, the child's siblings and the extended family. These included increased tolerance, a changed perspective on life and greater responsibility. Findler and Vardi (2009) examined the level of psychological growth in adolescent siblings of children with ID and the impact of certain perceived negatives on this level of growth. They found these siblings exhibited higher levels of psychological growth when compared to siblings of non-disabled children and, through examining other factors, noted that self-differentiation (termed here as independence and adaptive thought-emotion cognition) and perceived maternal preference contributed most greatly to this growth. The siblings of children with ID quantitatively reported discovering strengths and resources that were not necessarily present in others their age, taking on more responsibility, enjoying their lives and experiences more and developing greater sensitivity to others.

The current study aims to contribute to this expanding section of literature which aims to highlight the positives for families and, in particular, siblings of children with an ID by qualitatively examining the experiences of personal growth for adult siblings of children with an ID. Growth can be described as positive changes as a result of demanding or challenging circumstances (Tedeschi & Calhoun, 1995). Ryff (1989) also described growth as continuing to grow, develop and change as a person while maintaining previous positive characteristics. It is important to note that the definition Tedeschi and Calhoun (1995) use is in response to stressful life circumstances but, while this may be an important aspect of growth in siblings, the current study is not limiting growth to a response to the difficult experiences, but also in response to positive, fulfilling life experiences which have been reported across the ID literature (Stainton & Besser, 1998; Nelson-Goff et al, 2016; Taunt & Hastings, 2002).

Even among the positive psychology literature, siblings of children with ID have been neglected as a subject of research, with much of the research focussed on parents. In particular, there has been minimal research with adult siblings. What little there is among the psychology literature as a whole, has tended to focus upon potential stressors and, in particular, concerns over the future of their sibling with ID (Egan & Walsh, 2001; Orsmond & Seltzer, 2007). Therefore, this study aims to focus on positive aspects of the adult sibling's experience and highlight elements of personal and psychological growth both as a reaction to potential stressors and through fulfilling, positive experiences.

Method

Design

This was a qualitative study using semi-structured interviews to collect data. The interviews were transcribed and analysed using interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009).

Participants

Seven participants were included in the research, selected through purposive sampling. Participants were included if they had a sibling with a recognised intellectual disability, did not have an intellectual disability themselves, had some form of contact with their sibling every six months and were over the age of 18. They also needed to speak English. The participants were recruited through various means, largely through advertising online (N=5) but also through contact with an ID organisation (N=2).

Table 3 provides a summary of participant demographics. All the participants were women and described themselves as white British. They had an age range of 23-52 (M=34). Six participants had one sibling with ID while one had two. The siblings with ID had an age range of 19-51 (M=32). Five of the participants were older than their sibling(s) and two were younger. All the participants had lived with their sibling(s) when they were younger for an average of 18 years and a range of 15-20 years. As this was the first study to explore personal growth in adult siblings, the siblings of the participants had a range of disabilities and the current study aimed to produce results which were relevant across the ID spectrum.

Table 3: Summary of participant demographics

Participant Number	Age	Gender	Profession	Age of Sibling with ID	Frequency of Contact with Sibling	How long have they lived with their Sibling
01	23	Female	Care	19	Weekly	Until 18
02	32	Female	Care	38	4-6 weeks	Birth to 14/15 years old
03	30	Female	Care	27	2-3 times per week	20 years
04	52	Female	Care	51	Every week	Until 18
05	27	Female	Care	30	Live together	19.5 years
06	29	Female	Care	21 and 24	One 2-3 times a year and the other once a month	Until 18
07	47	Female	Care	46	Monthly	18 years

Procedure

The study was granted ethical approval by the University of Hull Faculty of Health and Social Care Research Committee. All seven participants contacted the lead researcher first, having heard about the research from elsewhere, either online or through a contact of the researcher. The researcher then sent them the participant information sheet and each participant was offered the opportunity to phone and ask any questions. If the participant wished to continue, the researcher liaised through email and organised a time and date for the interview to be conducted. Two interviews were conducted over Skype and five in person. In the case of the

Skype interviews, written consent and demographic information were obtained by the participant printing a copy of the consent form and demographic information sheet, signing them before scanning them on to the computer and emailing to the lead researcher. Interviews were conducted using a semi-structured interview schedule which was used as a guide, to ensure the truly subjective and personal experience of each participant was obtained. The schedule was largely concerned about areas of growth for participants, particularly any changes or development they felt were significant or meaningful. These changes could revolve around relationships, personal attributes or more practical life changes e.g. career. If the participant was struggling with the one-sided nature of the discussion, the researcher asked them to talk about experiences and memories with their sibling to encourage conversation. The researcher provided information at the beginning about their own understanding of personal growth to ensure the interview was given direction given the specific nature of the research. However, it was made clear that the interview was open-ended and all the participant's experiences were valued. The interviewer asked very few questions, relying largely on prompts (See Appendix I, interview schedule). This allowed the participants to largely lead the conversation and talk freely about their experiences. At the end of each interview, the interviewer ensured the participant was not distressed and offered some avenues of support which the participant could access if they were. The interviews lasted between 48 and 80 minutes. Each interview was audio recorded and transcribed before the data was analysed.

Data Analysis

IPA (Smith, Flowers & Larkins, 2009) was used to analyse the data as it allowed the researcher to explore the lived experience of the participants and capture their unique experience best while examining divergences and convergences among participants.

The analysis had three broad stages, following the guidance of Smith, Flowers and Larkin (2009):

- The transcripts were read through several times each to ensure the researcher fully immersed themselves in the data. The researcher then began to note down anything of interest while reading the transcripts. At this stage, the researcher did not have their research question in mind. The transcripts were then read through and quotes from each transcript were placed into descriptive codes.

- These descriptive codes were then clustered into themes for each transcript and combined with interpretative comments to reach an understanding.
- These themes were then compared across transcripts to find common themes.

Results

Table 5: Overview of themes.

Superordinate Theme	Subtheme
Developing Strength	Acceptance
	Resilience
	Advocacy
Learning	Values
	Unique Insight
Closeness	Family Unity
	Closeness with Sibling
	Pride

Three superordinate themes, each encompassing subthemes, were created from the data. Each theme involves an element of growth for the participants and aims to be as true to the original data as possible. The three superordinate themes show both reactions to the inherent difficulty associated with having a sibling with ID, as well as the apparent advantages and opportunities experienced by the siblings. To this end, the superordinate themes are: developing strength, learning opportunities and family closeness.

Developing Strength

Acceptance

Throughout the interviews, participants regularly described challenging experiences or difficulties but often coupled this with an expression of acceptance, as one participant explained:

"but no, I think it's funny… I think when I tell it to people they think I should feel worse about it but actually I don't.. I don't feel cross or anything, I just think "oh that's (name)..". P1.

"you know, obviously you wish it was different, you know, but it's not going to change, is it so it's just, kind of, just accepting that that's how it is really…". P2.

The difficulties described often involved loss of a normal sibling or wishing there was less added responsibility but participants regularly mentioned learning to *"try not to worry about the things that you can't change because I don't think that that has any positive effect on you at all"* P2.

As well as this acceptance of difficulty, was the acceptance of the sibling as the person they are and seeing them as 'their sibling', not a sibling with ID, as one participant explained:

"I would have accepted him or not, in the same way I would have accepted any other baby brother with, you know, great jealousy and what's this person doing taking me away… (laughs)" P7.

As with the first quote, there is an undertone here of acceptance despite what others in society might think. Many of the participants saw through the disability and were unwilling to view their sibling as a burden, despite the challenges, seeing the human being underneath:

"yeah and she's just so, I don't want to use the word loving because I hear it so much, like "oh people with Down Syndrome are so loving", it's not because she's got Down Syndrome it's just because of the person she is…" P5.

Resilience

This subtheme describes participant's experiences of learning to cope with difficulty and developing resilience through challenges associated with their sibling. Many participants described how they felt an added confidence in facing life's challenges and how certain things had "*not quite been so negative*" (P4) because of their experience:

"… and that we can cope with anything, I think that's one of the things that I've definitely grown up with… erm… that regardless of what life throws at you, you can definitely cope with it, you can deal with it… " P5.

"oh no, if I'd have had a child myself with a learning disability or born in similar circumstances, I think I would found it easier to cope maybe than someone who hasn't had that experience…" P3.

The added resilience the participants developed often developed through positivity, optimism and experience:

"and I think we're all a bit, you know, we've all grown up, you've just got to get on with life, you've not got to… we're all quite, sort of, positive people so… maybe that helped…" P4.

"Yeah, I think people think I'm, like, I have a lot more patience or time and things don't bother me as much that other people would be like, "argh"…" P2.

Interestingly, many of the participants were unwilling to say concretely that this resilience was directly due to their sibling and often phrased it as *"I can't pinpoint what made me…go for these changes…"* (P3) or seemed to doubt their own responses, "*I don't know if it makes you a bit more resilient almost?"* (P6), which appears to demonstrate how fundamental a character trait this resilience was for many of the participants.

Advocacy

An area of strength which came up consistently throughout the interviews was the idea of advocating and being strong for their sibling with ID. Many participants described feeling a need to fight for their sibling so they can achieve their goals and prosper:

"so I appreciate it's probably one of my things that I'm putting on to her but it would be good for her to be a bit more independent…" P5.

"it was almost , kind of, me being lairy and pushing for him that they listened and they moved him into somewhere that really meets his needs and stuff…" P2.

This level of advocacy often did not just apply to the participant's sibling but belied an underlying desire to advocate for all with ID, or even all people who could be deemed disempowered in society:

"So yeah and… I mean I don't actually jump up and down or do blogs or do big things to promote people with learning disabilities but it's certainly a vested area of interest for me…" P7.

"When it comes to ..like… people with disabilities… (unintelligible) I say what I think…" P1.

There was a clear sense of the injustice the participants felt, not just for their sibling, but disempowered people throughout society and a deep-rooted understanding and desire to advocate for this. This was perhaps demonstrated by the fact that all seven participants were in a caring profession.

Learning

Values

This subtheme involved the learning and development of skills and values which the participants felt were beneficial to them. For some, this meant an increase in tolerance of difference:

"*…maybe makes you more, more tolerant…*" P4.

"I don't think that you can have a fully, like, non-judgemental approach to things unless you grow up an environment where you kind of have to be like that." P5.

"…being a bit more open to people's differences and things like that…" P6.

For others, this involved an accelerated level of maturity:

"as an adult obviously he's six years older than me but I've always been kind of like the big sister…" P2.

"I think I was a lot more mature than many of my peers at school" P5.

There was certainly a balance to be struck with this theme as many of the participants framed their learning of skills in a positive way but often seemed to have no choice as to how fast they grew up or matured, as one participant explained, *"…that focus was on me…"*, (P6) suggesting that she had no choice but to grow up and succeed.

Many of the participants also recognised the importance of passing these skills to their children, family or the community and how beneficial this was to others:

"…with young children with siblings erm and I feel like, you know, I can give them advice and say, like, you know, "do this, do that"…" P1.

"…and I think my friends, it probably sounds a bit big-headed, but I think they probably are better people for knowing (name) as well…" P5.

Unique Insight

Participants all mentioned gaining an understanding and insight into the lives of others, particularly disabilities. Some described a greater confidence in taking on a job in ID:

"*and felt I had some skills, knowledge and competence in going into an area that I knew a bit about…"* P7.

"but I'd never worked in schools with people with learning disabilities or disabilities before so it was pretty much the fact that I had two brothers with disabilities, that kind of I think helped me get the job and stuff…" P6.

Others described a more generic understanding of other people often termed as, *"it's made me more, like, understanding of other people…"* (P1) or *"they feel that I understand, you know, that I've got some insight…."* (P2).

This generic insight was pervasive across the interviews and seemed to stem from an understanding of hardship but also a lack of reticence in interacting with and accepting difference:

"I can't tell you how many times I've heard people say to me "oh you're so good with kids" or so good with people who are struggling or whatever… and there's none of that yeah, worry about getting down and playing Lego" P5.

"I think when you've got a sibling with learning disabilities, you've probably got more understanding than those without…" P3.

Closeness

Family Unity

Participants spoke about unity with their entire family, in particular their parents and other siblings. For some of the participants, this meant relying on the nuclear family more for support, due to a lack of support elsewhere:

"*There's no support, there's no nothing, no erm.. so it's really just been a family thing… you know, it's all just always discussed within the family".* P4.

"Yeah… because we've got a really close… so we don't really have any family, there's just the four of us…" P5.

"*because there's no one else… it's just like us three, almost…"* P6.

Within this, participants expressed a siege-like attitude and a desire not to involve others, being able to cope without external support with one participant describing someone other than family caring for their sibling as *"…a horrible thought."* (P4) and another described her family's attitude as, *"we've managed to get that everything is okay kind of attitude…"* (P5).

Closeness with Sibling

Many of the participants described enjoying a close, inter-dependent relationship with their sibling which is particularly close due to their circumstances:

"think (name) and I are probably closer than a lot of siblings are because of that, because I've had to look after her but she still feels that she helps look after me because she's the bigger sister.." P5.

"My brother will say "he phoned me, he was looking for you"… I live in (place)! You know, he's phoning them so see where I am… but once he's spoken to you, he's fine.." P4.

"…that has made us very close in that sense, he know… I think he knows that, that I'm there for him…" P3.

One participant described having a close relationship with her sibling but did not feel it would be any different if he did not have ID:

"We're both, my brother and I are both united against the criticism from our parents… so we take it in turn to deflect, he's got some excellent strategies that I've learnt from…" P7.

One participant described struggling with her brothers due to their minimal interaction but described how she enjoys seeing them when she does:

"but yeah, I do like seeing them , I do like seeing them on Xmas day and New year, even if he can be a bit of a pain when I see them (laughs)" P6.

A lot of participants also reminisced about fun memories and experiences they had enjoyed with their sibling:

"it's nice that she was able to do those things and I guess like all the photos of us dancing together, it's quite nice that we did those together…" P5.

"*so I do have a lot of, like, positive interactions with him…"* P6.

"it's just brilliant and, um like, I just get so much enjoyment out of taking him places…" P1.

Often these positive stories followed accounts of difficult times or experiences for the participants, something which further underlined to the researcher the positive, resilient nature of those interviewed and the value placed on their sibling relationship.

Pride

Across the interviews, participants showed pride in their disabled sibling's achievements and found joy in the person they had become. One participant described her pride in her brother's reliability at work:

"*Well, I think we're pretty proud of him really..*" P4.

Another described how, while she wished her sister was given more independence, she was proud of what she had achieved:

"… and I'm really proud of her that she went to mainstream school…" P5.

Another sibling explained how her sibling struggles to find time to see her:

"you just don't know, I mean he's got his own place, he works, so he's employed…" P7.

Many of the participants recognised their sibling as a kind, caring person:

"*Yeah erm… that's good... he is very kind, he's so innocent, bless him"* P2.

However, there was an underlying sense that the participants felt an injustice for their siblings as their achievements were often dismissed or not recognised, as one participant noted:

"*I got my PhD a few years ago, (name) comes up to the graduation ceremony and we would go to the same things for him I think what's… what's often very sad is people see achievements through exam results..*" P4.

Another noted her brother's unrecognised skills:

"he might not be able to, like, read and write as some 6 year olds but he's got all that life experience and that other stuff... " P3.

Across the interviews, participants mentioned unfairness in society for their families and siblings and a desire to change this which tied in the advocacy subtheme. This is well captured by one participant:

"*how it can be quite easy to be like "oh it's the person with the disability that needs to change… and adapt when actually the way the society is sort of set up almost…"*. P6.

Discussion

The aim of this study is to highlight elements of personal growth qualitatively reported by adult siblings of people with ID. The literature in ID largely comprises of negatively slanted studies, focussing on the pathology and challenges for people with ID and their families (Dyson, 1996; Heiman, 2002). While many participants in this study expressed hardships and challenges associated with having a sibling with ID, they also demonstrated their often extraordinary resilience, and their ability to learn and grow. They also highlighted many joyous memories and experiences that come with having a sibling, disabled or otherwise.

Participants often discussed their duty or responsibility to their sibling, as well as things they have missed out on or neglected in their own lives due to having a sibling with an ID. However, there was often a statement of acceptance to counter this, suggesting they were at peace with this impact upon their lives, and did not wish for things to be different. Although acceptance may not be deemed ‘growth’ in itself, for participants in this study, acceptance appeared to be a foundation or a bedrock on which growth could manifest. Other literature has explored this concept of acceptance. Tedeschi and Calhoun (1996) discussed acceptance of what is changeable for people and what is not as an important aspect of the development of wisdom and growth in people who experience trauma. Further, Blackledge and Hayes (2006) found the use of Acceptance and Commitment Therapy (ACT) with parents of children with autism led to lower self-reported depression and higher self-reported global health. ACT involves the acceptance of difficulty while committing to development of the self, showing the importance of acceptance in developing and growing as a person.

In this study, acceptance laid the foundations for participants to develop resilience in the face of challenges and difficulties. This resilience also enabled participants to be strong for their sibling, which in turn meant they were able to grow into a strong person more broadly. Acceptance and resilience also meant participants enjoyed the positive experiences with their sibling, expressing no resentment towards them. This is consistent with previous literature, highlighting how resilience in light of one’s experiences encourages personal growth and strength of character, and allows people to prosper and develop further (Hauser & Welsh, 2002- In Boss.).

The strength and resilience participants developed allowed them to be strong on behalf of their siblings and advocate for them, often with the aim of improving their sibling’s experience and treatment. This often seemed to instil them with a desire to combat any inequality in society. Other research has highlighted similar findings in siblings of people with ID, including a desire to advocate for their sibling and a further understanding of societal injustices, underpinned by a level of acceptance and resilience (Rossetti & Hall, 2015; Hodapp, Urbano & Burke, 2010).

This bedrock of acceptance and resilience, as well as the participants' strength in advocating for their sibling, was a platform for them to develop and grow. Participants described developing maturity and insight through having a sibling with an ID. They also reported increased tolerance of difference, and developing a unique insight, whether that meant confidence in interacting with people with ID and understanding their difficulties, or a more generic perceptiveness and empathy. Participants described how growing up alongside their disabled sibling and having increased contact with other people with ID led to an increase in tolerance and acceptance of difference. Previous studies have highlighted accelerated growth amongst other siblings of people with ID. Hodapp et al (2010) analysed survey answers from siblings of children with ID and found that the majority reported greater empathy, opportunities to learn, compassion, responsibility and understanding of difference. Furthermore, Stainton and Besser (1998) interviewed families and parents who described increased tolerance and understanding for family members through having a sibling with ID.

Relative to siblings being more tolerant of difference, Allport's (1954) theory of social contact posits that increased contact between different groups decreases conflict and increases understanding, which is consistent with what participants reported here. Consistent with this theory, research beyond the family literature has shown the positive impact of increased contact with people with ID. Smith and Forrester-Jones (2014) analysed the journals of 62 students who had themselves completed research with people with ID and therefore experienced increased contact. They found that this increased contact led to more positive reflections about people with ID over time and a more positive attitude towards people with ID.

Moreover, several participants discussed a positive impact on their academic learning as they became involved in helping their sibling to read, write and develop. Some participants also mentioned an element of pressure to succeed academically in ways their disabled sibling could not. Although this was potentially spoken about in negative terms, the bedrock of acceptance and resilience allowed participants to prosper through this pressure, and have academic and occupational success. This finding appears to be unique to this study. Previous research has noted the often negative impact which having a sibling with ID has on non-disabled siblings' academic and school performances, often citing difficulty at school and a lack of parental resources due to their disabled sibling needing extra care (Dyson, 1996; Reichman, Corman & Noonan, 2008). However, there is very little literature exploring the long-term impact of having a sibling with ID on academic and occupational achievement and this is a potential area of future research.

Throughout the interviews, participants discussed the dearth of resources for families of people with ID and, in the age of austerity, the need for reliance on the immediate family for support. However, many participants discussed how their family would have been close without this being necessitated by a lack of resources, and described feeling close with their parents and siblings anyway. This siege-like mentality did not necessarily extend to all participants, but many discussed feeling close to their family through shared experiences. While other studies have found evidence of families containing a person with ID becoming closer and more tight-knit (Brown et al, 2003; Stainton & Besser, 1998), this finding is largely incongruent with other research. Studies have found that families containing a child with ID have poor organisation and support systems (Heiman & Berger, 2008); have more conflict (Margalit & Almougy, 1991) and experience more stress (Dyson, 1997). The results in this study suggest family functioning in ID still needs further exploration and there is a need to further explore the positive ramifications for families containing a person with ID.

The family unity reported in this study can be linked to resilience but appeared to manifest as a separate concept, that of family resilience, as opposed to the personal resilience described above. Family resilience has been well documented in the literature, with Bayat (2007) stating that being connected and pooling resources were both key factors in family resilience. Walsh (2003) also describes connected, communicative and flexible families as the most likely to display resilience. The participants in this study described closeness and communication with their family members and an ability to overcome difficulty and prosper. This was consistent with other studies (Crabtree, 2007; Kausar, Jevne & Sobsey, 2003) which found evidence of family members drawing on each other as sources of strength and resilience in order to face challenges and hardship.

Many of the participants discussed their close relationship with their sibling, whether that was reminiscing about fun memories they had shared, feeling close due to the responsibility they felt for their sibling or, as one participant described, having a normal brother-sister relationship. Many of the participants talked about taking genuine joy from experiences with their sibling, something which has been regularly reported across the limited sibling literature (Rossetti & Hall, 2015; Costigan, 2000). Other participants noted that, although their joyous experiences were rare due to circumstance, they were extremely special when they occurred.

A common theme across the interviews was pride in the ID sibling. This was often shown through pride in their sibling's achievements in employment or school but also about the kind, caring human being which they had developed into. This has been evidenced in other research done with siblings (Taunt & Hastings, 2002; Petalas et al, 2009). However, similar to the subtheme 'advocacy', many participants discussed the way society dismisses their sibling and is not willing to celebrate their achievements or recognise them for their ability, instead seeing the disability. This can be linked to the Social Model of Disability, a term coined by Mike Oliver (1983). This theory posits that people themselves are not disabled but it is systemic barriers, negative reactions and exclusion from society which disables people. Many participants in the current study alluded to this dynamic in their own lives, where their sibling's achievements and assets, be that diligence, kindness, art and many more, were largely dismissed or, at least, uncelebrated.

Limitations

One limitation of this study is the unrepresentativeness of the sample to the general population. All participants were white, British women, so the perspectives of the sample are those of a relatively narrow demographic. Also, there is likely a bias that people who volunteer for a study about personal growth may consider it important in their lives and those who do not would not have volunteered, suggesting this does not capture the experience of all adult siblings of people with ID. Further, given the caring nature of the participant's professions, it can be surmised that they may have held a bias towards positive thinking and it would be useful in future to explore any discrepancy between different population's attitudes towards personal growth in ID.

While the positives of having a sibling with ID are clear throughout the literature and have been found to be significant in the current study, previous research has noted that benefit finding can be interpreted as offensive by some individuals, particularly when the situation is deemed to be challenging (Tennen & Affleck, 2002). However, this study does not aim to minimise difficulty or deny the challenges for siblings of people with ID but explore positives, whether they stem from growth through that challenge or are explicit positives in their own right.

When introducing the study, the interviewer provided some information about their own understanding of personal growth and this may have biased the responses the participants gave. Participants were encouraged to discuss anything they wished to and the researcher made it clear all experiences were valuable. However, given the aim of the research, it was important to provide some direction to the participants in order to ensure relevant data was collected.

Given the researcher's own bias towards viewing ID in a more positive light, it was important to ensure this did not affect the results of the study. Regular supervision in which these issues were discussed and interaction with peer researchers allowed the researcher to remain grounded and helped in preventing bias in analysis. Further, codes and themes were produced in conjunction with the researcher's supervisor to ensure reliability. These codes and themes were also informally discussed with peer researchers who were familiar with the researcher's project.

Implications

No study previously has explored the personal growth of adult siblings of people with ID. These siblings occupy a unique position as they are able to look back on their childhood and teenage years and reflect on both difficult and joyous experiences while considering changes in their relationships, expectations and personalities. The results from this study provide an interesting perspective of the lives of these siblings and the ways they cope and develop resilience, the unique experiences and opportunities they have had and the way this has shaped them into caring, considerate human beings.

The results in this study add to the growing evidence suggesting there are multiple and varied benefits to having a sibling with ID. This evidence can help to alter the way society views people with ID in three ways: it can help change the views of researchers who favour a negative stance in their research into the impact of ID on family and loved ones; it can alter general society's view of the impact of ID and it can provide hope and optimism for children with disabled siblings and their families.

As mentioned previously in this study, research has largely focussed on the negative impact which ID can have on non-disabled siblings and their family (Benderix & Sivberg,2007; Bagenholm & Gillberg,1991). It is hoped that the positives highlighted in the current study can provide avenues for future research and help to continue the push towards more positive psychology literature, whether that be in resilience in non-disabled siblings and their family, the maturity and insight they develop or the unity which families show.

Secondly, this study also hopes to show ID in a different light in society. There is a large body of research which shows the beliefs of non-disabled people in society are a major barrier to people with ID across many areas, including school, transport, leisure and work (Office for National Statistics, 2014). Opinium (2013) carried out research in the United Kingdom (UK) and found 76% of respondents thought of people with ID as needing to be cared for, 85% believed there was at least "a little" prejudice to people with ID and 13% believed that people with ID got in the way some or most of the time. The current study hopes to show ID in a positive light and the positive impact people with ID can have on their non-disabled sibling. It is hoped that research like this can help to reshape the way people view ID and change the beliefs from ID being a burden to a blessing.

Finally, it is hoped that this study will provide hope and optimism to families who contain a person with ID. As mentioned previously, this study accepts the inherent challenges associated with ID but hopes other siblings may recognise personal growth reported in this study in themselves. The siblings in this study are uniquely placed to comment on the benefits and growth they have experienced throughout their lives, which may not have been obvious to them as a child or adolescent. This could provide optimism to younger siblings of disabled children and concerned parents who are worried about the impact of their disabled child on their non-disabled children, something widely reported in previous literature (Heiman, 2002; Waggoner & Wilgosh, 1990).

Conclusions

While this is by no means the first study to reject the negative, pathological stance of much psychology literature, it provides us with further evidence of the positives which are out there to be researched.

A consistent theme which emerged across the interviews was one of acceptance of the inherent challenges the siblings face and the consequent resilience which formed. Often, this was not explicitly stated by siblings but was alluded to with statements of acceptance following a difficult experience. Sibling's unique experiences also allowed them to develop their values and beliefs, be that tolerance, understanding, empathy or a fundamental sense of injustice on behalf of people with ID. This resilience and acceptance often appeared to act as a catalyst for further personal growth, allowing siblings to learn from mistakes and take more responsibility. This provides evidence that siblings do not just learn to 'cope' with their difficult experiences (Patterson, 1991; Gardner & Harmon, 2002), but thrive because of these, learning to enjoy positive experiences and maximise their learning.

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Part three: Appendices

Appendix A: Author guidelines for JARAD

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.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

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.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be pubished 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.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The Journal of Applied Research in Intellectual Disabilities encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

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.

The Journal of Applied Research in Intellectual Disabilities requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

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If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: http://www.wiley.com/go/funderstatement.

4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on ‘create an account’. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as separate files.

Please upload:

1. Your manuscript without title page under the file designation 'main document'.

2. Figure files under the file designation 'figures'.

3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and Letters to the Editor are accepted. 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. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the Journal of Applied Research in Intellectual Disabilities should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

APA - American Psychological Association

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

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article

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

Book Edition

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

6.4 Tables, Figures and Figure Legends

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, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures 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. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

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The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

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www.adobe.com/products/acrobat/readstep2.html

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

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Appendix B: NICE (2012) Methodology Checklist for Qualitative Studies

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		

3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:
Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example:	Clearly described Unclear	Comments:

• Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Not described	
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the	Rigorous Not rigorous Not sure/not reported	Comments:

results? - How systematic is the analysis, is the procedure reliable/dependable? - Is it clear how the themes and concepts were derived from the data?		
9. Is the data 'rich'? For example: - How well are the contexts of the data described? - Has the diversity of perspective and content been explored? - How well has the detail and depth been demonstrated? - Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: - Did more than 1 researcher theme and code transcripts/data? - If so, how were differences resolved? - Did participants feed back on the transcripts/data if possible and relevant? - Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example:	Convincing Not convincing	Comments:

• Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Not sure	
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting	Appropriate	Comments:

of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Inappropriate Not sure/not reported	
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + −	Comments:

Appendix C: Table 4: summary of the quality of the included studies.

Study	**Theoretical Approach**	**Study Design**	**Data Collection**	**Trustworthiness**	**Analysis**	**Ethics**	**Overall Quality**
Crabtree (2007)	Appropriate and clear	Appropriate design but unclear rationale	Inadequately reported	Clear and reliable	Adequate	Appropriate	+
Dyson (2010)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Good	Lacking	+
Heiman (2002).	Appropriate and clear	Appropriate design but unclear rationale.	Appropriate	Clear and reliable	Inadequate	Lacking	+
Kausar et al (2003).	Appropriate and clear	Defensible	Appropriate	Clear and Reliable	Very good	Appropriate	++
Kermanshahi et al (2008)	Appropriate and clear	Defensible	Appropriate	Unclear context but reliable methods	Good	Appropriate	+
Kimura & Yamazaki (2013)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Very good	Appropriate	++
Mardiros (1989).	Qualitative appropriate but unclear objective.	Unclear rationale.	Appropriate	Clear and reliable	Adequate	Lacking	+
Nelson Goff et al	Appropriate and	Defensible	Appropriate	Clear and	Very good	Appropriate	++

(2016)	clear			reliable			
Pillay et al (2012)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Very good	Appropriate	++
Rapanaro et al (2008).	Appropriate and clear	Defensible	Inadequately Reported	Clear and Reliable	Good	Appropriate	++
Rossetti & Hall (2015)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Very good	Appropriate	++
Stainton and Besser (1998)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Very good	Appropriate	++
Taunt & Hastings (2002)	Appropriate and clear	Defensible	Appropriate	Unclear context but reliable methods	Adequate	Lacking	+
Waggoner & Wilgosh (1990)	Appropriate but unclear	Unclearly explained design	Appropriate	Clear context but unreliable rationale.	Inadequate	Lacking	-
Yoong & Koritsas (2012)	Appropriate and clear	Defensible	Appropriate	Clear and reliable	Good	Appropriate	++

Appendix D: Data Extraction Form

Author(s)	
Year of publication	
Country of origin	
Aims of the study	
Participant demographics	
Methodological approach	
Data collection procedure	
Positives highlighted	
Quality assessment rating	

Appendix E: Participant Information Sheet.

Title of the study: The experience of personal growth in adult siblings of people with an intellectual disability.

We would like to invite you to take part in our research study. **This study is looking into the lived experience of personal growth for adult siblings of people with an intellectual disability.**

Before you decide if you want to participate in the study, we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You can talk to others if you would like before you decide if you want to take part and **the researcher will answer any questions you may have.**

What is the purpose of the study?

- The sibling relationship is one of the most important relationships in many people's lives. The purpose of this study is to attempt to understand the experience of having a sibling with an intellectual disability. Specifically, this study is interested in experiences of personal growth.
- Personal growth can be described as continuing to grow and develop as a person. The inherent challenges associated with ID have been heavily researched but this research is interested in experience of personal growth despite these challenges.

Why have I been invited to take part?

- This information is being given to people who are over the age of 18 and have a sibling with an intellectual disability who they have contact with at least twice a year. You have been given this information as it is felt you fulfil these criteria and may be interested in sharing your experiences in the interests of research.

Do I have to take part?

- *No, **participation is completely voluntary.***
- If you decide to participate you will be asked to sign a consent form to indicate that you agree to take part.
- You are free to withdraw and stop your involvement with the study up to the point where the study results are analysed and written up and you do not have to give a reason for this.

What are the possible disadvantages and risks of taking part?

- Participating in the study will require about 85 minutes of your time. It won't necessarily take this long and we can take breaks, but this may be inconvenient for you.
- Some people may find it distressing to talk about their experiences. If this happens, your researcher will offer support within the session and help you to gain access to further support from your clinical care team and/or your GP. Also, the research interview can be paused or stopped at any point.

- Further information can be provided by the researcher to provide you with support if you feel you need this after the interviews have been completed.

What are the possible benefits of taking part?

- We cannot promise that you will have any direct benefits from taking part in the study.
- However it may be a personally rewarding and enjoyable experience to share your experiences with another person.
- It is hoped that the research will help us to understand more about learning disability and aid in improving care and support for people with an intellectual disability as well as family and carers involved with intellectual disability.
- The hope is that by improving our understanding of personal growth in intellectual disability, we can help improve services and support as well as bringing personal growth and positive change further to the forefront in people's understanding of intellectual disability.

What will happen if I decide I no longer wish to take part?

- You are free to withdraw from the study before the results are analysed and the study is written up; you do not have to give a reason to withdraw.

What if there is a problem or I want to make a complaint about the study?

- If you have any concerns about the study you can contact the researcher or their supervisor, who will do their best to answer your questions.

Will my personal details be kept confidential?

- Yes, all the personal information that you provide will be kept strictly confidential.
- Any information that could be used to identify you will not be used in the research.
- Participants will be assigned a code to protect their anonymity. Any identifiable data from the study will be kept on a secure encrypted memory stick, and any information linking data and personal information will be stored securely in a separate location.
- Any information that could identify you as a participant will be destroyed once the research is completed, and anonymised data that cannot be linked back to you will be kept securely for ten years.
- The only time that information cannot be kept confidential is if you disclose something in our meetings that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact the appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

What will happen to the results of the study?

- The results from all participants will be analysed and presented in a report written for a scientific journal and as part of a thesis project. The results will also be presented at research conferences and professional development events, and possibly wider media.

- Your personal details and any identifiable data will ***not*** be used in the research write-up or in these events, but anonymised quotes may be used.
- If you wish, you will be given a brief written summary of the findings of this study once it has been completed.

Who is organising and funding the research?

- This study is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull and sponsored by the Humber NHS Foundation Trust. Some sections of data collected during the study that are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities, to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

- The study is reviewed by an independent organisation called a ***Research Ethics Committee***. The Research Ethics Committee protects the interest of people who participate in research. This study has been reviewed by the Faculty of Health and Social Care at the University of Hull and has been approved.

If you have any further questions regarding the study, please contact Joshua Wigley.

Thank you for taking the time to read this information.

Joshua Wigley

Trainee Clinical Psychologist.

This study is supervised by Dr Nick Hutchinson, Clinical Psychologist.

Further Information

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Appendix F: Consent Form

CONSENT FORM

Title of the study: The experience of personal growth in adult siblings of people with an intellectual disability.

Name of Researcher: Joshua Wigley

Participant Identification Number:

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study. ☐
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
3. I understand that my interview will be audio recorded, and that anonymised quotes may be used for the research. ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, up until the data is analysed. ☐
5. I agree to take part in the above study. ☐

Please circle an option

I would like be given a brief written summary of the findings of this study once it has been completed. YES / NO

Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person Taking Consent	Date	Signature
____________________	____________________	____________________

Appendix G: Sources of Support Form

Sources of Support in Learning Disability

The British Institute of Learning Disability (BILD) provides support on their website.

http://www.bild.org.uk/information/relationships/

http://www.bild.org.uk/information/help/

http://www.bild.org.uk/information/useful-resources/

The following link contains factsheets for a range of areas in learning disability

http://www.bild.org.uk/information/factsheets/

MENCAP is an organisation which also provides support

Call: 0808 808 1111

This link provides further information: https://www.mencap.org.uk/about-learning-disability

You may also wish to visit your GP for further support

Appendix H: Demographic Information Sheet

Information about you

Please tick ☑

1. **What is your age in years?**

....

2. **Are you male or female?**

Male ☐ Female ☐ Prefer not to say ☐

3. **Which ethnic group describes you best?**

☐ White British
☐ Other White background
☐ Black British
☐ Black African
☐ Black Caribbean
☐ Other Black background
☐ Indian
☐ Pakistani
☐ Other Asian background
☐ Black Caribbean and White
☐ Black African and White
☐ Asian and White
☐ Other Dual Heritage
☐ Chinese
☐ Traveller
☐ Bangladeshi

4. **How old is your sibling?**

…………………..

5. **How often do you have contact with your sibling?**

…………………..

6. **Have you ever lived in the same house as your sibling and for how long?**

Thank you for completing this questionnaire

Appendix I: Interview Schedule

Interview Questions

Introduction: “It is common in research regarding intellectual disability for researchers to ask about negative aspects of people’s lives and the negative impact it has had on them. However, in this research I am interested in finding out the positive impact your sibling’s intellectual disability has had on your life, in particular your experiences and any positive or meaningful changes these have elicited for you. In particular, areas of personal growth. That is, growth and development as a person.”

It may help to think of this as a one-sided conversation, led by you.

I know the information sheet talks about personal growth. I was wondering what that means to you and how that might have been a part of your experience?

Can you tell me what it is like having a sibling with a learning disability?

Can you tell me a little bit about your sibling?

Can you tell me a bit about your relationship with your sibling?

Can you think of any memorable experiences involving your sibling?

<u>Prompts</u>

- “In what way was this a positive or meaningful experience for you?” “Has this experience changed you in any way?” “What constitutes a meaningful change for you?”
- “Has this changed relationships? View of yourself? Lifestyle? Outlook on life? Beliefs?”

- “How does this make you feel? “How do experiences like this make you feel?”…
- “In what way might your life be different to people who do not have a disabled sibling? Do you feel as though you have experienced areas of personal growth which other may not?
- “Could you tell me anymore about this change?” “Is there anything which increased or speeded up this change or anything you can think of which may have done so?”

To elicit responses, I would use prompts and probes to ask participants to explain answers more or to find out exactly what they mean by something.

Ending: “How has this conversation been for you?” “Is it different than other conversations you have had about your sibling’s learning disability?”

“Thank you for your time”.

Appendix J: Epistemological Statement

Epistemology refers to how we understand knowledge and the way we can gain knowledge (Willig, 2013). The following statement explains the epistemological stance of the researcher; their underlying assumptions and beliefs that might influence the research.

Interpretative Phenomenological Analysis (IPA) was used as a means of analysing data in the empirical part of this portfolio thesis. Largely, IPA is used to understand the subjective and personal perspectives of the participants in the sample under investigation (Lester, 1999). The researcher in the current study was particularly interested in the individuals that were participating and their lived, personal experience. That is, what is their experience of growth in their life.

IPA encourages researchers to use the experiences and views of their participants in order to obtain knowledge about the phenomenon under investigation. In this sense, this could be deemed a realist approach in that there is an objective truth to be found (Willig, 2013). However, IPA also acknowledges the impact of the researcher's own beliefs and values in interpreting this 'truth'. Indeed, IPA holds that the researchers beliefs and values are assets which can aid the researcher in making sense of the other's experience. At the same time, IPA acknowledges the importance of the different ways people experience the same things and the different meanings they ascribe to things. In this sense, this could be deemed a more social constructionist view as it is our internal world which organises and ascribes meaning to external occurrences, rather than the external determining our perception of it.

However, IPA is largely focussed upon what is important to the participants themselves and is interested in their truth about a certain thing. In this study, that meant their understanding and experience of having a sibling with an intellectual disability. In this sense, a more phenomenological stance more appropriately describes the epistemology underpinning IPA and, indeed, the researcher's own epistemological stance.

Understanding a person's personal reality was important to the researcher and IPA allowed this to be explored in depth. What was especially important to the researcher was understanding the meaning of participant's experience, why it was important to them as well as to their broader social and cultural context. Therefore, more specifically, the researcher would consider themselves an interpretative phenomenologist (Smith, Flowers & Larkin, 2009).

Having decided upon this epistemological stance, IPA appeared to be the most appropriate methodology and allowed the researcher to remain true to the values highlighted above. What was particularly important to the researcher was that the participant's true account of their experience was reported and, to this end, an inductive analysis was completed when the results were coded and themes were generated. This meant the researcher allowed themes to emerge without considering previous research and findings. While this was more difficult having completed reviews of the literature while preparing to complete the study, the researcher felt strongly that previous literature should not affect the analysis.

It is also important to note the researcher's stance regarding disability and the distaste they hold for the current, negative slant which dominates the ID literature. While there is a place for research into challenge and difficulty, the researchers feels passionately that there is a need for more positive research and a move towards studying the good and fulfilling elements of all areas of psychology, including ID. These opinions certainly influenced the research and would inevitably have affected the researcher's views when analysing and even collecting the data. Again, however, IPA recognises the importance of the researcher's own interpretation of the findings and, indeed, believes that these can add to and supplement the findings, using the researcher as a tool in analysis.

References

Lester, S. (1999). An introduction to phenomenological research. Taunton (UK): Stan Lester Developments.

Willig, C. (2013). Introducing qualitative research in psychology. McGraw-Hill Education (UK).

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

Appendix K: Reflective Statement

At the beginning of this Doctorate, I distinctly remember how intimidating the thought of completing a thesis was and the daunting prospect of planning and organising it made the decision about what to focus on very important. Initially, I was put off focussing my research on intellectual disabilities (ID) because I felt that spending three years researching the challenge and difficulty associated with it was not something I wanted to do. This had not been my experience of ID, having volunteered with a charity in the North West for five years which takes children with a range of disabilities on three different holidays every year. While caring for a young child 24/7 for a week sounds like a challenging experience, that has not been my experience, or the experience of any of my friends who also attend the holidays. If I had not enjoyed it so much, I would not have returned every year. People often discuss how they come on the holidays as a way to "boost their CVs" but are soon hooked and return year after year. My experience was one of fun, laughter and fulfilment in the job I was doing. I also met many inspiring relatives of people with ID, both volunteers with the charity and family members of the children we took away on holiday. Often, these were some of the most patient, kind and compassionate people I have been fortunate enough to know and provided me with great inspiration and guidance while on the holiday.

Thus, my initial research focus led me elsewhere. However, I clearly remember receiving teaching in the first year of the Doctorate which focussed on dementia and, more specifically, the subject of "living well" with dementia and old age. This concept was completely new to me, remarkably, and was not something I had thought about in great depth. However, I really liked the idea of "living well" in spite of and because of something perceived as challenging and difficult. It was not long before I made the link between this concept and my own experience of ID and, more specifically, the experience of my friends and peers who had relatives with ID.

I made contact with Dr Hutchinson, my supervisor throughout this project, and, between us, we came up with an empirical project and a literature review which were both unique in the context of the literature and linked to my personal experience.

From here, my research progressed through the completion of several proposals and evolved slightly as the first and second years of the Doctorate passed. By the middle of my second year, I was ready to apply for ethics and get on with the project. However, passing ethics was one of the most frustrating parts of the entire project as I was completely taken aback, perhaps naively, by the depth of examination from the committee and the exacting corrections they provided. While this was a difficult part of the project for me, I am, in retrospect, extremely grateful to the committee for the advice they gave as it was very useful and contributed to the project being credible and of a good standard.

I received ethical approval in the summer of 2016 and the relief I felt was enormous as I could now begin my research proper, canvassing for participants and beginning to think about the process of data collection. Organisation has never been a strong suit for me and working out how to find, contact and meet up with participants caused me great anxiety. However, I got extremely lucky in this regard. I contacted dozens of groups and organisations with no luck but one group online happened to contain a lecturer who worked at a large university. I do not know the lecturers name or anything about them, I only found out they had been so helpful through a participant, but I will be eternally grateful to them for mentioning my research in a lecture and prompting several of their students to contact me about participating in my research. I was able to travel to meet the participants in a two day stint of interviews and this really got the ball rolling and gave me the confidence to go and find more participants. At this point I must acknowledge how grateful I was to my participants for their flexibility in meeting with me. None of the participants I spoke to were willing to conduct the interviews in their home, something I must admit I found incredibly frustrating at first when I saw my female colleagues having no issues in this regard. However, I recognised how understandable this was with hindsight and recognise the lengths they all went to in order to meet with me, many travelling and being flexible with last minute changes to our meeting point or meeting time! I am also grateful that they were all so accommodating and made me feel at ease. I was pleasantly surprised that my nerves were not completely all-consuming when conducting the interviews and I was able to conduct what I felt were good, flexible, participant-driven interviews. Again, I think this is largely down to the participants being so open and allowing me to relax and largely just listen.

As 2017 arrived, I recognised how close the deadline was and really began to think about the writing up process. My SLR had been progressing okay, despite the challenges I had faced. My initial search terms had thrown up close to 10,000 results which I was forced to dredge through, many about completely random subjects such as trains. However, while this was frustrating, it was an extremely fulfilling experience to finally have a final set of papers. My data collection was also progressing well and, by February, Dr Hutchinson advised to cease collecting data unless somebody specifically asked to participate. Reflecting back on the data collection process, I was very pleased with how surprisingly well it had gone and I was pleased with the quality of the data I had collected.

Something I had initially considered a challenge, the commute to York over the winter of 2016-17, actually turned out to be something of a blessing. I regularly stayed over on Monday and Tuesday nights and enjoyed the sights and restaurants of York and these evenings gave me ample time to complete any transcriptions or trawl through my SLR initial search results. This meant that I had completed my transcription largely by the end of January and felt I was ahead of the game going into final stretch.

While the final months before hand in have been challenging and required flexibility in coping with placement, academic work and research, I have been extremely lucky in having people around me who have kept me relaxed and reminded me that there are things outside the course. Whether it's sending an amusing message over social media, visiting me or allowing me to visit them, listening while I drone on about my research or taking me out for meals, coffees and, most importantly, beers, I have benefitted greatly from their company. The write-up has been a challenge because I have, in the past, struggled to create a coherent story throughout essays and I spoke in-depth with my supervisor about this and how I can ensure I make both my SLR and empirical paper into a well written piece of research. I have worked hard and I greatly appreciate the advice others have given me regarding structure and writing style.

I have found writing this statement to be a cathartic and interesting experience. I had plans for particular things I wanted to mention within it but others came to me spontaneously while writing and I think that has allowed me to reflect on the process and how my experience has been one of some downs but many ups. I remember a conversation with a peer in September 2016 when we debated the year ahead. We wondered whether, as it was an entire year of our lives, whether we should ensure we have some fun and do not let our theses completely consume us until June and, in fact, whether this would be beneficial to the process, or whether we should completely commit to the thesis and work extremely hard all year, regardless of the sacrifice. On reflection, I'm not sure there is a black and white answer to this question but I feel as though I have managed to find a happy middle ground in which I have been able to produce a good piece of research which I am proud of while enjoying the time I have had and maintained a good work/life balance.

I think this is one of several lessons I have learned through the process of completing a doctorate in Clinical Psychology. Another is the importance of organisation, I have improved immeasurably in this regard since 2014 and now maintain both a social and work diary and aim to get things done earlier than I would have previously. I have also learnt the power of the subconscious and how, if I am struggling to complete a task, it is often incredibly helpful to switch to something else, often finding that it seems much simpler on my return. I think I have learned to handle anxiety and tolerate stress as well as embrace the unknown. I have learned not to be too hard on myself, academically, socially and emotionally but recognise the importance of pushing myself to achieve.

The skills I have learned and the personal growth I myself have undergone throughout the last three years will hopefully hold me in good stead for whatever I end up doing once the course finishes in September. I will do my best to succeed in the next chapter of my life and will endeavour to work hard to achieve that success, but not too hard.

Appendix L: Worked example of descriptive coding and interpretative commentary.

Interpretative Comments	Transcript	Codes
Feels like would have been different without sibling? Could be interpreted as subjectively "better" without sister or "worse"? Dad's pride in her for being so confident. Strange that she reports having more knowhow and confidence than her Dad… suggests growing up with someone more conducive to understanding than raising someone. Still not 'second nature' to Dad to interact with ID despite 30 years experience with his daughter. Interesting comparison with parents. Becoming 'second nature' for her as she has done this her entire life, developed understanding and reduces preconceptions. What would she have been like? Almost as though it's so normal for her that she forgets other people might not have contact with ID and it might be a novel experience. Is this a worry for her?	05 Yeah (laughs)… so when I said "not the person I would have been" so erm… something my dad says a lot is when we go out to, like there's a (PLACE NAME) group and I did a lot of work at a place called (PLACE NAME) which is for children for learning disabilities and autism and he always said "I'm amazed that you just go in and talk to everybody and you don't seem to worry about how you're going to come across if you don't understand what they're saying, it doesn't ever come across…" he said "obviously I've known (NAME) for 30 years but I still get really anxious that if I'm talking to someone with a learning disability and I don't understand what they say, I'm going to come across as rude or whatever…" I Yeah 05.. so I think me not knowing any different means I don't have any preconceptions or worries… I Mhmm 05.. and I wouldn't have been like that without (NAME)… erm… I imagine cause a lot of people, you know, when they've got a new friend who comes home or I start	Wouldn't be the same without sibling. Volunteering with people with ID. Dad amazed by me. Not worrying about interacting with ID. Parental anxiety surrounding interacting with ID despite experience. Parents worried about offending people with ID. Don't know any different than my sister- don't worry about meeting others with ID. Wouldn't be the same without sibling.

Not embarrassed by sister here but hints at embarrassment perhaps as a child? Reminiscing about sister	seeing someone in a new relationship, that's always a think, if you've not grown up with it, do they know what to say? Do they know how to respond when she's not making any sense? Or, you know, banging on about Gladiators again (laughs)..	Friends and partners not knowing how to interact with people with ID. Worrying that sister is making sense. Wondering whether sister is 'banging on' about Gladiators to visitors.
Different world view to others… understands difference and diversity. Again compares herself to her hypothetical self, grateful for the experience her sister has provided.	I Okay (laughs) 05 … whereas I think for me, I'm.. because of K I've grown up to be just so open to all experiences with somebody and not to… yeah… I think I see things very differently to I would have done without her…	Being open to all experiences. Seeing things differently compared to if didn't have sibling with ID.
Shows her values here… uses peoples' non-judgement with her sister as barometer for their quality as a friend. Shows importance of her relationship with her sister? She and her sister come as a package? Who is it an extra thing to worry about for? Her or her friends and partners? Shows how much she values her sister's abilities, in this case as a "judge of character". Recognising skills and abilities of sibling.	I Mhmm.. did you notice a difference with peers…? 05 Yeah… erm… yeah and I think, I think it is a good thing… so I've always judged whether I'm going to stay friends with somebody or stay in a relationship on how they've reacted with (NAME)… and although that seems like an extra level to have to think about or worry about… she's just a good judge of character that I think, if she doesn't get on with somebody, it's probably good for me to know because they're not worth knowing much longer anyway (laughs)..	Judging whether to remain friends with someone based on their reaction to sister. Recognising that this may be an extra thing to think about. Sibling as a good judge of character. If sibling doesn't like someone they're not worth knowing.
Dissemination of 'growth' to friends, learning to cope with challenges and learning to accept diversity. Pride? That she can pass this on to her friends.	I Okay (laughs) 05.. and I think my friends, it probably sounds a bit big-headed, but I think they've probably are better people for knowing K as	Friends become better people for knowing sibling.

Again comparison to hypothetical self who would be ‘worse?’ without sister.	well, for having to grow up and.. yeah, see some things they saw or.. when we have sleepovers and things… yeah and I think that, kind of, non-judgemental thing goes with that so I don’t think I would have been as non-judgemental as I am because of it…	Friends and I become less judgemental because of things we saw growing up.

Appendix M: Ethical Approval

Removed for hard binding