Oxford Doctoral Course in Clinical Psychology

THE EXPERIENCES OF PARENTS WHO HAVE A CHILD WITH AN INTELLECTUAL DISABILITY

Jonathan Codd

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The Experiences of Parents who have a Child with an Intellectual Disability

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Abstract

Parenting a child with an intellectual disability is associated with high levels of challenges and increased parental stress. Interpretive Phenomenological Analysis (IPA) is a qualitative research methodology that has been increasingly used to explore the experiences of parents of children with intellectual disabilities.

The first paper is a systematic review which identifies the range of IPA research exploring the experiences of parents who have a child with an intellectual disability and evaluates the quality of papers. Twenty studies were identified, findings of which were critiqued and synthesised. The review found that parents of a child with an intellectual disability experience a range of difficult emotions and practical difficulties, and that the level of parent coping is related to external support. Studies showed strengths in most areas of methodological rigour pertinent to the quality of IPA. Areas for improvement included reflexivity, ethical considerations, justification of research design, and use of an inclusion and exclusion criteria in participant sampling. Future research should be conducted across a wider number of countries and cultures and with an increased focus on the experiences of fathers and older parents.

The second paper presents an IPA study that explored the lived experiences of parents who had a child with an intellectual disability transitioning to adulthood. Transition to adulthood is an important life stage for young people and may be particularly challenging for people with intellectual disabilities. Ten parents were

interviewed. The interviews were analysed and revealed three superordinate themes. These captured parents' experiences of difficulties and uncertainty related to their role, their child's independence, navigating services for their child, and accessing support for themselves. Increased collaboration and consistency from statutory services is required in addition to providing emotional support to parents and facilitating parent support networks.

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Firstly, I would like to thank all the parents who gave their time to participate in this research. This project would not have been possible without them and it was a privilege to hear their experiences. It has refreshed the respect I have for all the parents and carers who devote their lives to supporting and caring for their loved ones to provide them the best quality of life possible. This includes people in my family, particularly my parents, who inspire me every day in their love, care and devotion to others.

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Oxford Doctoral Course in Clinical Psychology

Paper A

A Systematic Review of IPA Studies Exploring the Experiences of Parents who have a Child with an Intellectual Disability

Jonathan Codd

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Abstract

Background: Interpretive Phenomenological Analysis (IPA) has been increasingly used across cultures to explore the experiences of parents and carers of children with intellectual disabilities. The current review aimed to systematically identify, synthesise and evaluate the quality of this research.

Method: A systematic search was conducted across databases EMBASE, MEDLINE, PsycINFO, CINAHL, WEB OF SCIENCE, AMED, BNI, HEALTH BUSINESS ELITE and PubMED and by entering key search terms into Google Scholar. Twenty studies were eligible for review, grouped into three categories (health-related; parent role and identity; and lifespan-related) and findings were compared. The studies were also appraised against a quality checklist.

Results: In terms of data synthesis, four overall concepts were evident across the three categories of studies: the difficulties of parenting a child with an intellectual disability; support from others; parent coping and self-care; and knowledge, certainty and control. Studies showed strengths in most areas of methodological rigour pertinent to the quality of IPA. Areas for improvement included reflexivity, ethical considerations, justification of research design, and use of an inclusion and exclusion criteria in participant sampling.

Conclusions: Findings unilaterally indicate that parents who have a child with an intellectual disability experience a range of difficult emotions and practical difficulties, and that the level of parent coping and external support received have an important influence. Future research using IPA with parents who have a child with intellectual disability requires increased researcher reflexivity and all studies should clearly state ethical approval. Research should be conducted across a wider number of countries and cultures and with an increased focus on the experiences of fathers and older parents.

Keywords: learning disability; intellectual disability; Interpretative Phenomenological Analysis; interview; parent; systematic review

Proposed Journal: British Journal of Learning Disabilities (See Appendix A for author guidelines)

Accessible Summary

- We looked at twenty research studies which used interviews to explore what it is like for parents who have a child with an intellectual disability. We looked at how well this type of research is done.
- Being a parent of a child with an intellectual disability can be difficult and emotional. Parents do not always feel in control and know what is going to happen in the future to their child and this can be stressful. Parents need lots of help from family, friends, and professionals. Keeping busy, working and doing leisure activities can help parents to cope better.
- Researchers were mostly good at following guidelines for doing a good study like picking a new and interesting topic and explaining how their results are important. Researchers need to be better at saying how their own beliefs, ideas and experiences may affect their research.
- These findings can help people understand more about parents who have a child with an intellectual disability. It may give professionals ideas about how they can help parents. It could help make future research studies better. More research with parents needs to be done across different countries. Research should include interviews with fathers as well as mothers, and also with older parents.

A Systematic Review of IPA Studies Exploring the Experiences of Parents who have a Child with an Intellectual Disability

Defining Intellectual Disability

'Intellectual disability', and similar terms such as 'learning disability', 'learning difficulty', and 'mental retardation' have historically been used interchangeably, creating confusion throughout research (Harris & Greenspan, 2016). The term 'intellectual disability' is used in the current review as it represents an international shared language and has widely replaced the term 'mental retardation' (Salvador-Carulla et al., 2011; British Psychological Society (BPS), 2015). Intellectual disability indicates developmental difficulties in both intellectual and adaptive functioning, which must have been present before adulthood (World Health Organisation, 2007; BPS, 2015). People with intellectual disabilities are more likely to have co-morbid physical and mental health problems (Cooper et al., 2015) requiring additional support.

The worldwide prevalence of intellectual disability has been reported to be 10.37 per 1000 population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). In the UK, approximately 1.5 million people have an intellectual disability (Mental Health Foundation, 2018). However, the prevalence of intellectual disability cross-culturally is difficult to estimate because different definitions may be used, those including deficits in social and occupational functioning and those which rely solely on a measure of intelligence quotient (Allison & Strydom, 2009).

Parental Experiences

Until the 1980s, people with intellectual disabilities in the UK mostly lived in long stay institutions. Nowadays, whilst many people with intellectual disabilities access statutory or third sector support (Hatton, Glover, Emerson & Brown, 2016), it is family

members, particularly mothers, who provide the most support to their children with intellectual disabilities(McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006) and the most common living situation for adults with intellectual disabilities in England is with family or friends (Hatton et al., 2016).

In contrast to the dearth of literature exploring the views of people with intellectual disabilities, there has been a long tradition of research involving family carers as research subjects (Grant & Ramcharan, 2002). Hollins and Hollins (2005) describe the difficulties for parents raising children with intellectual disabilities, from infancy through to adulthood. This may be a different experience to raising a child without a disability which is likely to have a practical and emotional impact on parents. The term ‘parent’ is used in the current review to refer to the person or people who undertake primary parental responsibility for the individual with an intellectual disability. This is often mothers and fathers but may also extend to other family members, adoptive parents and foster parents.

Stress and Burden in Parents

Parents of children with intellectual disabilities are significantly more likely to experience parenting stress than parents of children without an intellectual disability (Hassall, Rose & McDonald, 2005; Dyson, 2003). Parenting a child with an intellectual disability is often a significant time commitment which may impact on health, wellbeing, work and financial income (Hatton et al., 2016; Adult Social Care Statistics Team, Health and Social Care Information Centre (ASCSTHSC Information Centre), 2017). It may affect parents’ relationships with their spouses and makes it harder for parents to spend time with other family members (Yoong & Koritsas, 2012).

Most of the variance in the stress of parenting a child with an intellectual disability has been explained by parental locus of control, parenting satisfaction and child

behaviour difficulties (Hassall et al., 2005). This demonstrates the potential importance of parental cognitions influencing parental stress levels, as highlighted in Lazarus and Folkman's (1984) transactional stress and coping model. The single most important predictor of parental stress was the negative definition of the situation. For mothers, this was associated with the behavioural problems of the child whereas, for fathers, related to the experienced social acceptance of the child (Saloviita, Itälinna and Leinonen, 2003). Parents have also reported experiencing stress and tension as a direct result of insufficient and unreliable support services (Griffith et al., 2011).

Parent Coping

To provide optimal care for their children, parents must possess sufficient emotional and coping resources, manifested in capacities such as taking others' perspectives and regulating impulses (Rholes et al., 2006). Al-Yagon (2015) found significant differences in parental coping strategies between parents of children with and without intellectual disabilities. Fathers of children with intellectual disabilities reported higher avoidant attachment, lower anxious attachment, lower negative affect, lower usage of child-related active coping strategies, and a higher level of sense of coherence than mothers. These findings highlight the potentially important role of parental emotional resources (attachment and affect) in explaining parents' coping resources.

Parent Support

Levels of parent stress are affected by social support in the form of marital happiness, family social climate, and social networks (Hassall et al., 2005). However, support services often caused additional problems for families, rather than alleviating the burden of care (Griffith & Hastings, 2014). Over a third of carers reported that it was difficult to find information and advice (ASCSTHSC Information Centre, 2017). Between

2007 and 2015, fewer family carers of an adult with intellectual disabilities received a direct service for themselves as carers, whilst numbers of family carers receiving information, advice, and signposting plateaued (Hatton et al., 2016). The reason for this reduction is unclear but suggest large numbers of parents may feel unsupported and inadequately informed. This lack of support may result in increased stress and burden on parents and families.

Positive Parent Experiences

Several studies have identified positive experiences of parenting a child with an intellectual disability. Parenting can be rewarding and empowering; increase personal strength and confidence; and provide companionship, hope, love, and joy (Willingham-Storr, 2014; Yoong & Koritsas, 2012; Beighton & Wills, 2017; Griffith & Hastings, 2014).

Previous Reviews

Recent years have seen an increase in qualitative studies involving parents and carers of children with intellectual disabilities. Qualitative approaches may provide in-depth descriptions of parental experiences and the meanings derived from their experiences. Fishwick (2009) reported overarching themes from papers that explored the experiences of parents raising a disabled child. Themes included two risk factors (experiences and challenges) and two protective factors (strategies for coping and support). Willingham-Storr (2014) identified four key themes across six UK-based studies: impact upon families; service provision and support networks; coping; and transition. Griffith and Hastings (2014) identified five primary themes in their review of research that explored the experiences of parents of children with intellectual disabilities and challenging behaviour: love, altered identity, crisis management, support is not just

'challenging behaviour' services, and the future: low expectations, high hopes. More recently, Davys, Mitchell and Martin (2017a) identified eight themes from their review of papers that explored the experiences of fathers: response to diagnosis; varied response to intellectual disability; concern for the future; work; roles and relationships; impact of fathers upon child development; fathers and service providers; and fathers' needs and coping strategies.

Current Review

In line with previous reviews, the current review aimed to review research regarding parental experiences of having a child with an intellectual disability. However, the current review focused on studies using Interpretive Phenomenological Analysis (IPA) methodology. IPA is concerned with understanding lived experience and how participants make sense of their experiences (Smith et al., 2009). Although IPA has been increasingly used across a variety of cultural populations to explore the experiences of parents and carers of children with intellectual disabilities, to the author's knowledge no study has systematically reviewed this research. There have now been a significant number of IPA studies in this area which warrants a systematic review highlighting the key findings and the quality of the research. IPA is a popular and increasingly used qualitative approach and therefore it is necessary to review the quality of the research using this methodology with various populations. Reviewing the quality of the IPA research enables researchers to reflect on areas of strength as well as aspects requiring further consideration and improvement. Reviewing the key findings across studies allows people to understand better the experiences and support needs of parents who have children with intellectual disabilities.

Aims

The current review aimed to systematically identify, synthesise and evaluate the quality of research using IPA to explore the experiences of parents of children with intellectual disabilities. The major research questions were:

1) What are the main findings, conclusions and themes arising from IPA studies focusing on parental experiences of having a child with an intellectual disability?

2) To what extent do studies using IPA with parents of people with intellectual disabilities demonstrate methodological rigour according to quality standards for IPA research?

Method

Search Strategy

A systematic search was conducted on 19th January 2018 across databases EMBASE, MEDLINE, PsycINFO, CINAHL, WEB OF SCIENCE, AMED, BNI, HEALTH BUSINESS ELITE and PubMED. The following search terms were employed:

1. parent* OR carer* OR caregiver* OR famil* OR mother* OR father* OR maternal OR paternal

   AND
2. child* OR offspring OR kid* OR young* OR young person OR young adult OR young people OR teen* OR youth* OR adult child*

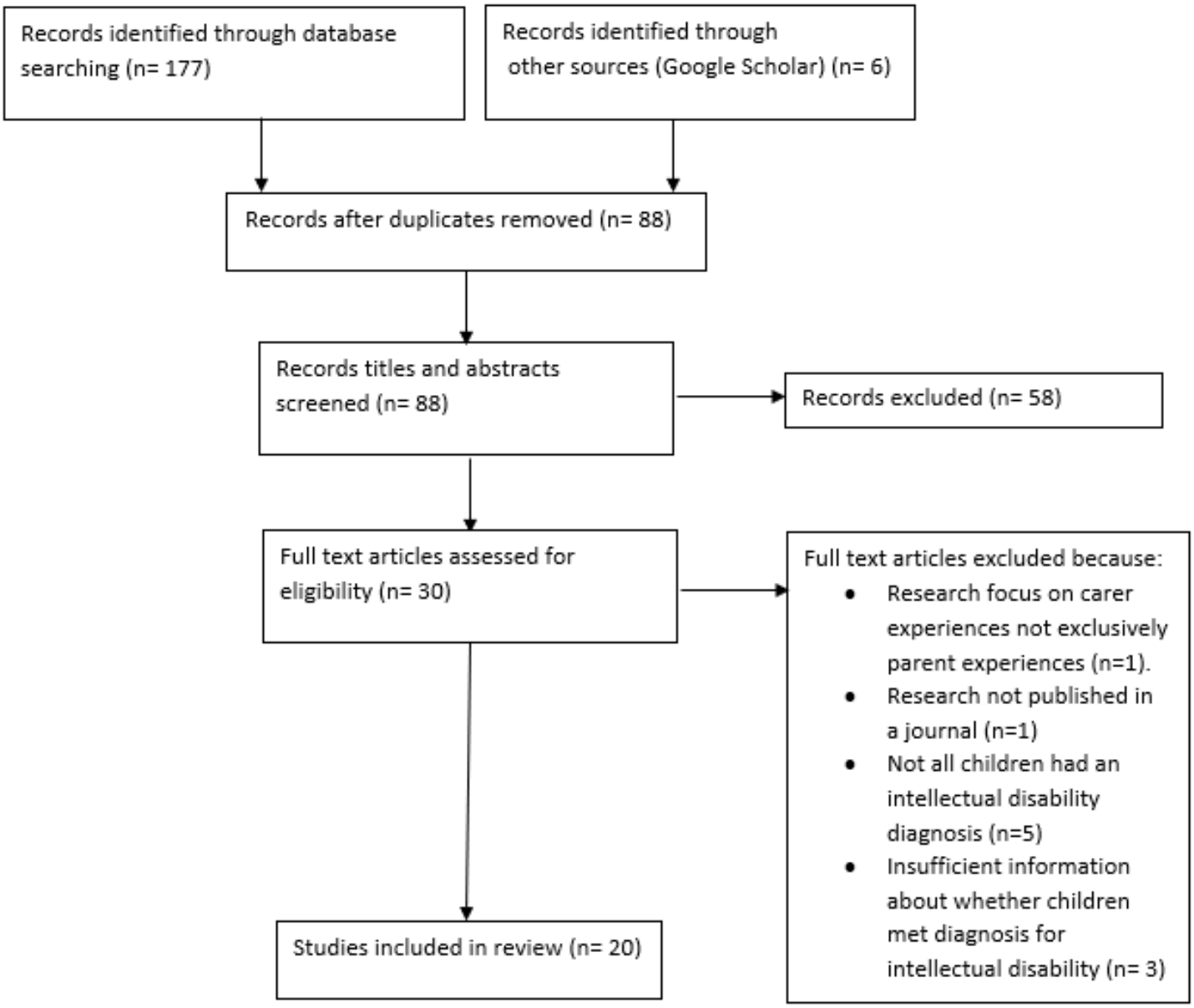
   AND
3. amentia OR cognitive impair* OR developmental disord* OR exceptional adult* OR intellectual disabilit* OR intellectual developmental disorder OR learning disabilit* OR learning disabled OR learning disorder OR mental retard* OR mentally retard* OR oligophrenia OR slow learner OR special need*

AND

4. interpretative phenomenolog* OR IPA

Search terms were based on database-generated pseudonyms for ‘intellectual disabilities’, including cultural variations in language, to maximise inclusivity. The initial search identified 177 articles. After duplicates were removed, 88 article titles and abstracts were screened for eligibility. After screening, 30 full text articles were assessed. A further search was conducted by entering key search terms into Google Scholar which generated 6 additional articles. Reference lists were hand-searched from papers that met inclusion and exclusion criteria. A total of 20 studies were eligible for review. Figure 1 shows the process of study selection.

Figure 1. A flow diagram of the systematic paper selection process



Inclusion and Exclusion Criteria

Studies were screened and assessed using the criteria outlined in Table 1.

Table 1.

Inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Studies must have: • Used IPA methodology. • Focused on parental experiences of having a child (of any age) with an intellectual disability (WHO, 2007). Studies were not excluded on the basis of family members with an intellectual disability having additional mental or physical health diagnoses. • Been published in a peer-reviewed journal.	Studies were excluded if they: • Were not written in, or translated into, the English language. • Focused on parental experiences of an intervention, group or service (e.g. GP, physical health services, parent to parent support). • Included other participants who were not parents of people with an intellectual disability. • Included parents of children without an intellectual disability and did not separate the views of parents of children with intellectual disabilities and parents of children with other diagnoses (e.g. Autism Spectrum Disorder).

Data Synthesis

Due to the broad range of topic areas, synthesis was achieved by categorising studies according to the topic focus of each paper and then reviewing the research findings of each paper. Findings were compared across studies in each category, and similarities and differences in themes were considered. Categorisation was guided by the judgement of the author with the use of supervision. Half of the topics appeared to be health-related as they included parents' experiences of events such as having a child diagnosed with an intellectual disability; having a child with intellectual disability admitted to hospital; and having a child with an intellectual disability who died. In considering the remaining studies, six appeared to be related to parent role or identity such as being a father of a child with an intellectual disability and working alongside caring, and four studies appeared to be related to specific life stages such as parents' experiences of pre-school children with intellectual disabilities and experiences of having a child with an intellectual disability transition to adulthood. One limitation of categorising studies in this way is that some categories included more studies than others and therefore there were fewer results and themes to synthesise in the lifespan-related and parent role and identity studies compared to health-related studies. Another limitation is that, despite categorisation, there remained considerable variance of topic focus across studies in each category.

Other methods of synthesising qualitative research (see Barnett-Page & Thomas, 2009) were considered but declined for not meeting the review purpose. Although all studies employed an IPA methodology, and are therefore likely to share a similar epistemological stance which would support the use of a formal synthesis, the studies explored a broad range of topic areas and therefore drawing interpretations across the papers would be difficult using a formal method of data synthesis.

Quality Appraisal

Studies were critically appraised to assess quality and credibility. There is not an agreed process regarding the critical appraisal of qualitative research, although checklists have been developed (Smith et al., 2009). The current review used all items from the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006), which has previously been developed to appraise the report of qualitative research. Additional items were included from well-established guidelines for qualitative studies (Yardley, 2000; 2008; 2017), specifically for IPA methodology (Smith et al., 2009), incorporating recent ideas on quality from Larkin and Thompson (2012) and the importance of reflexivity (Finlay, 2002; Shaw, 2010; Gough, 2017). Appendix B shows the checklist used for the critical appraisal. Appendix C is a completed checklist for one study.

Individual topics were rated as 'strong' if all criteria were evident and clearly described in a paper. Topics were rated as 'weak' if there was no evidence of any criteria being met or if the criteria were not clearly described in a paper. Topics were rated as 'mixed' if there was evidence of some criteria with other criteria missing, or if some of the criteria were not clearly described.

Following data extraction, each study was given an overall rating of 'strong', 'mixed', or 'weak', based on numbers of 'strong', 'mixed' and 'weak' ratings across the twelve topics, along with the researcher's opinion of the study in its entirety. This was important due to some criteria overlapping across topics. For example, the rating of the topic 'reflexivity' impacted on the rating of the topic 'data analysis' as criteria for this included the researcher critically examining their own role, potential bias and influence during analysis and selection of data presentation. Each topic was given an overall rating of 'strong', 'mixed', or 'weak', based on numbers of 'strong', 'mixed' and 'weak' ratings across the twenty studies. Topics were rated as 'strong' overall if more than half of the

studies were rated as ‘strong’ and no more than one study was rated as ‘weak’. Topics were rated ‘weak’ overall if more than a quarter of studies were rated as ‘weak’.

Overall ratings indicated the extent to which the authors adhered to methodological rigour according to quality standards for IPA research. The researcher’s supervisor rated a subsection of studies to provide inter-rater reliability.

Results

Summary of Studies

Twenty papers met the inclusion criteria. Over half of the studies were conducted in the UK (*n*= 13) with other studies carried out in Sweden (*n*= 2); Australia (n=1); Romania (*n*=1); South Africa (*n*=1); and Taiwan (*n*=2). A total of 215 participants were recruited to the studies. Six studies focused on experiences of mothers, two on experiences of fathers, and twelve used a mixed sample. Year of paper publication ranged from 2003 to 2017. Table 2 provides a summary of the studies.

Table 2.

Summary of studies included in the review

Study	Aim	Data Collection	Participants	Results and Themes
Agbenyega & Tamakloe 2014 Australia *Asian Journal of Inclusive Education*	Build on informal relationships with parents who have children with disability, to create personal and meaningful conversations about how they negotiate kindergarten choice dilemmas.	• Parents recruited through a poster display at two schools. • One group discussion and face-to-face individual interviews as a follow-up. • Data recorded and transcribed. • Transcriptions for each parent were sent back for cross-referencing before analysis.	Parents of children with moderate ID (IQ scores ranging from 36-51). Parents- N= 4; Age Range: 31-43, *M*= 36.0; Gender: NR; Ethnicity: NR. Children- N= 4; Age Range: 4-4, *M*= 4.0; Gender: 4 males; Ethnicity: NR; Severity of ID: moderate	• Historical construction of disability/normalcy played a role in how some parents made school choices. • Parents expressed opinions that depicted stress trust issues. • Importance of family changes, feelings of hurt and apprehension, and discussions about children's futures.
Barr & McConkey 2007 UK *Journal of Research in Nursing*	Gain an understanding of the experience of parents who have a child referred for genetic investigation	• Pre-appointment self-completion questionnaires (N=19). • Semi-structured interviews with parents (N= 18). • Second interview with parents for whom genetic investigation were continuing nine months following initial appointment (N= 9).	Biological parents. Parents- N= 19; Age Range: 22-47, *M*= 35.6; Gender: 12 females, 7 males; Ethnicity: NR. Children- N= 12; Age Range: 0-14, *M*= 3.5; Gender: NR; Ethnicity: NR; Severity of ID: NR.	• Seeking information – the wider context. • A different type of appointment. • Interpreting information and experiences. • Parents' changing perspectives.

Study	Aim	Data Collection	Participants	Results and Themes
Boström & Broberg 2014 Sweden *Journal of Intellectual Disability Research*	Explore fathers' experiences of parenthood in relation to a child with ID from the initial diagnosis to 5 years later.	• 8 fathers signed a written consent to participate in interviews (as part of a mailed-out questionnaire for a larger study). • 3 separate interviews conducted between 2005-2010.	Biological fathers. One father excluded as child's diagnosis of ID ruled out at 5-year interview. Parents- N= 7; Age Range: 25-43, *M*= 33.9; Gender: 7 males; Ethnicity: NR. Children- N= 7; Age Range: 0-5, *M*= 2.1; Gender: 4 males, 3 females; Ethnicity: NR; Severity of ID: NR.	• An interrupted path – no longer taking things for granted: reactions to their children's diagnosis. • Being a good father: overall perceptions of their parenting of a child with ID. • Dealing with the unexpected: individual ways of integrating, managing, and living with the knowledge of their child's disability over the 5 years.
Chou, Fu & Chang 2013 Taiwan *Journal of Applied Research in Intellectual Disabilities*	Explore how working mothers in Taiwan reconcile their paid work with caregiving for an adult child with ID.	• Participants recruited through a census survey on health and social care issues in a city in Taiwan (N = 796). • Working mothers recruited through 2 parental organisations and 3-day care service centres throughout Taiwan. • One-to-one interviews ranging 50-120 mins, between 2008-2009.	Mothers younger than 65 years old working 30+ hours each week with adult family member who had significant intensive care needs, aged 18+ years and lived with family without residential care. Parents- N= 15; Age Range: 41-56, *M*= NR; Gender: 15 females; Ethnicity: NR. Children- N= 15; Age Range: 19-33, *M*= 24.1; Gender: 8 females, 7 males; Ethnicity: NR; Severity of ID: 5 moderate, 5 severe, 5 profound.	All mothers prioritised caregiving over paid work. Strategies used to make paid work fit with caregiving included: • Strong social networks and informal support for their care work. • Use of formal services. • Personal religious beliefs and positive attitudes towards care. • Flexible working hours due to self-employment. • Good relations with employers. • Working positions. • Work locations.

Study	Aim	Data Collection	Participants	Results and Themes
Chou & Kröger 2014 Taiwan *Health and Social Care in the Community*	Use the approach of social capital to analyse reconciliation between work and family for Taiwanese lone mothers of an adult child with ID.	• Participants recruited from parental groups, day care centres and a survey. • One-to-one interviews, 50-120 minutes, in Mandarin or Taiwanese, tape-recorded and transcribed. • Researchers mailed transcripts and telephoned participants to check errors or misunderstandings.	Working lone mothers with an adult child with ID. Parents- N= 11; Age Range: 43-60, *M*= 51.6; Gender: 11 females; Ethnicity: NR. Children- N= 11; Age Range: 20-33, *M*= 26.8; Gender: 6 females, 5 males; Ethnicity: NR; Severity of ID: 1 moderate, 6 severe, 4 profound.	• Care capital was limited and was lost, gained and lost again during life-cycles of care-giving. • Guanxi (social networking to create good relationships), proved to be the sole source of care capital, making reconciliation between work and care responsibilities possible. • In the absence of support, religion and the mother–child relationship was a care capital.
Clarke, Thompson, Buchan & Combes 2007 UK *British Journal of Learning Disabilities*	Explore parents' experiences of pain and discomfort in their adult children with ID who are unable to verbally communicate their pain effects on parents.	• Information sheet sent to all parents fulfilling criteria (n = 46). • First eight respondents selected for individual interviews. • Interviews were 20-90 mins, audio taped and transcribed.	Parents living with adults with LD and limited verbal communication using a health respite service. Parents- N= 8; Age Range: 44-84, *M*= NR; Gender: 6 females, 2 males; Ethnicity: NR. Children- N= 8; Age Range: 20-48, *M*= NR; Gender: 6 females, 2 males; Ethnicity: NR; Severity of ID: NR.	• Not seeing son or daughter in much pain. • Identifying pain/working out what's wrong. • What is done about pain. • Interactions with services. • Effects on parents.

Study	Aim	Data Collection	Participants	Results and Themes
Collins & Coughlan 2016 Romania *Journal of Policy and Practice in Intellectual Disabilities*	Explore mothers' experiences of the disclosure process of their child's disability and how disability legislation affects caring.	• Interviews were 75 mins, interpreted, audio-recorded and transcribed. • Participants were asked if they wanted to validate their transcript. • English translations of dialogues transcribed and checked by the interpreter.	8 mothers. Parents- N= 8; Age Range: NR, *M*= NR; Gender: 8 females; Ethnicity: NR. Children- N= 8; Age Range: 10-18, *M*= NR; Gender: NR; Ethnicity: NR; Severity of ID: 7 of children had 'multiple disabilities' and 1 had a 'severe mental disability'.	• "Uncertainty" surrounding diagnosis and towards professionals caused by gaps in the disclosure process. • "Disempowering bureaucracy" while striving to meet the annual requirements of their local Disability Commission. This impeded mothers access to community support and contributed toward a lack of understanding of child's needs.
Davys, Mitchell & Martin 2017b UK *British Journal of Learning Disabilities*	Exploration of the lived experiences, roles, needs and concerns of fathers of adults who have a LD.	• Organisations passed information sheets to potential participants. • 9 fathers contacted and 7 agreed to participate. • One-to-one semi-structured interviews, about 75 mins, audio-taped, and transcribed.	Fathers of children diagnosed with ID. Parents- N= 7; Age Range: 60-70 *M*= 62; Gender: 7 males; Ethnicity: NR Children- N= 7; Age Range: 20-50, *M*= 32; Gender: 6 males, 1 female; Ethnicity: NR; Severity of ID: NR	• Shocked at LD diagnosis but reported adaptation over time. • Impact of LD, perception of their adult child and roles they assumed varied. • Valued support from wives and grandparents, having knowledge and interests, and work-type roles. • Concerned about the future yet comprehensive futures planning were lacking. • Difficulties being emotionally open, referring to societal stereotypes. • Valued positive support from service providers, but relationship was often in conflict.

Study	Aim	Data Collection	Participants	Results and Themes
Docherty & Reid 2009 UK *Journal of Applied Research in Intellectual Disabilities*	Explore the implications of independent living or continued dependency of young adults with DS as expressed by their mothers.	• 10 women responded to an invitation in the national DS organisation newsletter. • 2 women not included as children not left school. • One-to-one interviews, 45-60 mins, recorded and transcribed.	Mothers of young adult children diagnosed with DS. Parents- N= 8; Age Range: 50-61, *M*= 56; Gender: 8 females; Ethnicity: NR. Children- N= 8; Age Range: 19-29, *M*= 23; Gender: NR; Ethnicity: NR; Severity of ID: NR.	Mothers described themselves as having a dynamic role as gate-keepers and facilitators in aiding their child on the path to adulthood. Themes were: • Identifying the stages of development: 'What's the next stage?' • Defining and shaping adulthood: 'What are you going to be doing?' • Gate-keeping and facilitation on the path to adulthood. • Self-reliance and independence as a value, goal and cultural norm.
Elford, Beail, & Clarke 2010 UK *Journal of Applied Research in Intellectual Disabilities*	Examine the experiences of parents of adults with ID of dealing with restraint, and implications for professionals.	• Professionals within ID services were contacted to pass study information to families who showed interest and met inclusion criteria. • 6 interviews lasting 45 min-2 hours, tape recorded and transcribed verbatim.	Parents had a relative aged 16+ with an ID and challenging behaviour, currently or previously lived with the person, and had used any form of restraint with their relative. Parents- N= 7; Age Range: 47-78, *M*= NR; Gender: 6 females, 1 male; Ethnicity: NR. Children- N= 6; Age Range: 21-34, *M*= NR; Gender: 5 males, 1 female; Ethnicity: NR; Severity of ID: All had severe ID.	• Experience of the parenting role and relationship. • Relationships with professionals and services. • Decisions about restraint.

Study	Aim	Data Collection	Participants	Results and Themes
Faust & Scior 2008 UK *Journal of Applied Research in Intellectual Disabilities*	Gain an understanding of the experiences of parents who have an adolescent child with ID and mental health difficulties.	• Parents known to services as well as carers groups were invited to participate. • 23 families were contacted, and 14 parents participated. • Interviews 1-3 hours, audio recorded and transcribed.	Parents had a child aged 16-25 years with an ID and current or past mental health problems. Parents- N= 14; Age Range: NR, *M*= NR; Gender: NR; Ethnicity: Of 11 families 6 were South Asian, 4 White British or European, and 1 Black African. Children- N= 11; Age Range: 17-24, *M*= 19.9; Gender: 7 males, 4 females; Ethnicity: See above; Severity of ID: 1 borderline-mild, 4 mild, 3 mild-moderate, 2 moderate, 1 severe.	• Struggle to understand: struggling in the dark; playing detective; searching for a cause; needing to know. • More pain: fresh wound; extra care and pressure; suffering and loss; living with fear; living with blame. • Trying to get by: existing not coping; isolation. • Battle for help: not listening to us; waiting for us to break; inadequate provision.
Hatton, Akram, Robertson, Shah, & Emerson 2003 UK *Journal of Applied Research in Intellectual Disabilities*	Provide a rich picture of the experience of disclosure for South Asian parents of a child with severe ID.	• Parents contacted through local services. • Phase 1- interviews averaging 2 hours with 26 families. • Phase 2- structured interviews (cross-sectional survey) with 136 parents of a child with severe ID. • Phase 3- 30 min semi-structured interviews with 20/26 parents from phases 1 and 2.	South Asian parents of child with severe ID. Parents- N= 31; Age Range: 23-51; *M*= 36.5; Gender: 25 females, 6 males; Ethnicity: 24 Pakistani and 2 Bangladeshi families. Children- N= 26; Age Range: 2-19, *M*= 11.1; Gender: 12 females, 14 males; Ethnicity: See above; Severity of ID: All children had a severe ID.	• Experiences of disclosure varied; many parents experienced this in the wrong language with little post-disclosure support. • Good practice was viewed as: prompt disclosure in the appropriate language; partners present; emotional support; clear and practical information; post-disclosure support from keyworker. • Good practice associated with understanding the child and being more likely to mobilise supports.

Study	Aim	Data Collection	Participants	Results and Themes
Hatton et al. 2010 UK *Journal of Applied Research in Intellectual Disabilities*	Explore: 1) perceptions of causes, meaning, and impact of challenging behaviours; 2) experiences of services; 3) differences within and across ethnic groups.	• 23 minority ethnic community families invited from an NHS database. • Interviews were 45-120 mins, audio-recorded and transcribed (and translated into English if necessary).	14 families were interviewed. All had a family member with ID living with them. Carers- N= 14; Age Range: 33-70, *M*= NR; Gender: NR; Ethnicity: NR (only as from '7 local majority' and '7 minority ethnic groups') Children- N= 14+; Age Range: 'Adolescents and young adults', *M*= NR; Gender: NR; Ethnicity: See above; Severity of ID: NR	• Range of difficulties with adult with ID. • Varied relationships with local communities in acceptance and support. • Varied but largely negative relationships with services. • Varied relationships with person with ID, from highly dependent with negative consequences to more fulfilling. • Families from minority ethnic communities more likely to report negative experiences.
Heer, Larkin, Burchess, & Rose 2012 UK *Advances in Mental Health and Intellectual Disabilities*	Explore the cultural context of care-giving amongst South Asian communities caring for a child with ID in the UK.	• Participants recruited from two pre-existing carer groups. • Two focus groups conducted. • Focus groups were up to 75 mins, audio-recorded, transcribed and translated into English.	Parents- N= 9; Age Range: NR, *M*= NR; Gender: 5 female, 4 males; Ethnicity: One focus group were Sikhs born in India, the other group were Muslims born in Pakistan. Children- N= 9; Age Range: 7-19, *M*= 14.7; Gender: 7 males, 2 females; Ethnicity: See above; Severity of ID: 5 recorded as ID and 4 as severe ID.	• Making sense of disability (God's choice, focus on epilepsy and ''bad'' behaviour, a problem with expression, struggling to get a diagnosis, and medical negligence as a cause). • Feeling let down by services (anger at unresponsive GPs, feeling blamed by services, and difficult interactions with ''Asian'' service providers). • Looking to the future (concerns for future well-being and wanting help versus giving up).

Study	Aim	Data Collection	Participants	Results and Themes
James 2016 UK *Journal of Intellectual Disabilities*	Explore family carers' experience of admission of their relative to an NHS Assessment and Treatment Unit (ATU) and relationship with professionals.	• Parents contacted through Local Health Boards. • Semi-structured interviews were 50-75 mins, recorded, and transcribed verbatim.	6 parents with frequent contact with adult children with ID previously admitted into an ATU and preferably discharged within the last 6 months. Parents- N= 6; Age Range: NR, *M*= NR; Gender: 3 females, 3 males; Ethnicity: NR. Children- N= 4; Age Range: NR *M*= NR; Gender: 2 females, 2 males; Ethnicity: NR; Severity of ID: NR.	• Role of carer as impacting on self • Self as impacting on the role of carer • Preserving a sense of self • Self as vulnerable • Valuing support for self Experiences had significant influence on sense of value and self-identity resulting in higher levels of anxiety, stress and uncertainty about the future of relatives and their identity as carers. Professionals identified as having a pivotal role influencing how carers view their sense of self, identity, value and importance.
Olsson & Roll-Pettersson 2012 Sweden *European Journal of Special Needs Education*	Investigate experiences of parents of pre-school children with ID within the Swedish social support system	• Recruitment obtained through department heads of 2 central habilitation centres. The first 5 volunteering families from each centre were contacted. • Interviews were 60-90 minutes, audio-taped and transcribed verbatim.	13 parents of 10 children who had contact with a habilitation centre at least one year prior to the study. Parents- N= 13; Age Range: NR, *M*= NR; Gender: 10 females, 3 males; Ethnicity: NR. Children- N= 10; Age Range: 3-7, *M*= 5.2; Gender: 5 females, 5 males; Ethnicity: NR; Severity of ID: 1 child had severe ID. 6 had DS and 4 had 'another' syndrome.	• 'Orchestrating formal support' entailed being strategic, expressing oneself in specific ways, and taking on the role of coordinator, actively arranging collaboration between different organisations. • 'Early intervention'- Syndrome-specific groups provided information which parents used to obtain support from the municipality and habilitation. • 'Informal support'.

Study	Aim	Data Collection	Participants	Results and Themes
Pownall, Jahoda, Hastings & Kerr 2011 UK *American Association on Intellectual Developmental Disabilities*	Contrast parents' experiences of supporting similarly aged siblings with and without ID around sexual development.	• Participants recruited through links with a voluntary organisation. • Interviews were one-to-one, lasted an average of 60 mins, audio recorded and transcribed verbatim.	8 mothers of a child with ID and a child without disabilities of the same gender no more than 5 years older or younger. Parents- N= 8; Age Range: 45-53, *M*= 48.0; Gender: 8 females; Ethnicity: NR. Children- N= 8; Age Range: 17-19, *M*= 18.0; Gender: 4 males, 4 females; Ethnicity: NR; Severity of ID: Children able to provide a verbal account of daily events and describe their feelings.	• 'Balance between independence and control'- Acknowledgment of the sibling's sexuality was demanded by increasing autonomy, whereas continuing dependence of child with ID hindered mothers. • Supporting child's sexuality- 'sexuality' brought to light mothers' fears about their child's ability to cope with adulthood challenges. • Discussion of sexual matters and sources of information.
Reilly, Huws, Hastings, & Vaughan 2008 UK *Journal of Applied Research in Intellectual Disabilities*	Explore experiences of mothers who lose a child with ID regarding issues relevant to services, researchers and medical professionals.	• Participants recruited as part of a larger project. Information sent to support groups, hospices and services in the UK. Flyers forwarded to relevant families. • Participants drawn from a group of 35 bereaved mothers. • Telephone interviews were 60 mins, recorded, and transcribed. • 9 interview transcripts were selected for analysis.	9 parents whose child had died at least 12 months previously. Parents- N= 9; Age Range: 26-62, *M*= 47.6; Gender: 9 females; Ethnicity: NR. Children- N= 9; Age Range: 1-18, *M*= 10.6; Gender: 6 males, 3 females; Ethnicity: NR; Severity of ID: 1 child was described as 'profound and multiple ID'.	• 'Loss'. • 'Benefit finding'. • 'Coping'- continuing in a caring role by working within the world of ID. • 'Sources of support'- support from similarly bereaved parents was the most useful source of support, although it was not always readily accessible. • 'Medical relationships'

Study	Aim	Data Collection	Participants	Results and Themes
Reilly, Huws, Hastings, & Vaughan 2010 UK *Intellectual and Developmental Disabilities*	Explore experiences of 6 couples whose child with DS and a congenital heart condition (CHC) had died.	• Recruitment by a UK charity offering support and information regarding heart conditions associated with DS. • Parents interviewed separately, and on different days. • Interviews were 60 mins, recorded, and fully transcribed.	6 married couples, whose child with DS and a CHC had died at least 12 months prior to being approached. Parents- N= 12; Age Range: 43-76 *M*= 54.8; Gender: 6 males, 6 females; Ethnicity: NR.	• Dilemmas regarding dual diagnosis • Treatment decisions during the life and the death of their child (‘‘We had to make a decision’’) • Couples coping (‘‘We weren’t really going through it together’’)- differences between couples existed in their experiences of coping and supporting each other. • Ripples from the child’s life.
Sandy, Kgole, & Mavundla 2013 South Africa *International Nursing Review*	Investigate support needs of caregivers of children with LD.	• Purposively selected families of children with LD who attended a community clinic for supportive counselling and prescribed medication. • Phase 1- interviews with caregivers of one family at a time. Interviews were 60 mins. • Phase 2- follow-up interviews to explore and clarify issues from phase 1 interviews. All interviews were audiotaped and transcribed verbatim.	5 parents with children with LD. The 3 families selected had attended the clinic over 10 years. Parents- N= 5; Age Range: NR, *M*= NR; Gender: 3 females, 2 males; Ethnicity: NR. Children- N= 3; Age Range: NR, *M*= 15.0; Gender: NR; Ethnicity: NR; Severity of ID: NR.	• Caring: a stressful experience- perceived as difficult and frustrating yet rewarding. • Partnership • Training and education- difficulties compounded by caregivers’ lack of skills and knowledge. • Supervision • Financial assistance • Discriminatory practices- Stigma was reported, sometimes involving overt acts of discrimination and social exclusion that further added to frustration.

Key: ID= intellectual disability; LD= learning disability; DS= Down syndrome; NHS= National Health Service; NR= not recorded

Data Synthesis

The studies were grouped into three categories: health-related studies; parent role and identity studies; and lifespan-related studies. Findings across each category are discussed in turn.

Health-Related Studies

Ten health-related studies included papers focusing on assessments and treatments (James, 2016; Barr & McConkey, 2007); mental health (Faust & Scior, 2008); pain (Clarke, Thompson, Buchan, & Combes, 2007); challenging behaviour (Hatton et al., 2010; Elford, Beail, & Clarke, 2010); diagnosis and disclosure (Hatton et al., 2003; Collins & Coughlan, 2016); and death (Reilly et al., 2008; Reilly et al., 2010).

Difficulties of parenting. Across most health-related studies there were themes of parent stress including frustration, worry, isolation, and pressures of responsibility, in terms of the parent role and making important decisions. The impact of uncertainty was particularly poignant. Results are congruent with the extensive literature describing parents of children with intellectual disabilities as significantly more likely to experience parenting stress than parents of children without intellectual disabilities (Hassall et al., 2005; Dyson, 2003), and many reporting feeling tired, stressed, depressed, and isolated (ASCSTHSC Information Centre, 2017)

Support from others. Most studies reported that parents lacked support from others, predominantly services and professionals, with regards to information, advice, openness, consistency, and promptness. These findings highlight the importance of social support for parents of children with intellectual disabilities, with previous research reporting levels of parent stress are affected by levels of formal support from professionals and social support from partners, family members and friends (Hassall et

al., 2005). Findings regarding the perceived lack of support from services and professionals is in line with studies identifying that parents experienced stress and tension due to insufficient and unreliable support services (Griffith et al., 2011; Griffith & Hastings, 2014).

Parent coping. Some studies (e.g. James, 2016; Clarke et al., 2007; Faust & Scior, 2008; and Reilly et al., 2008) reported findings relating to parents' resilience, coping mechanisms, and strategies. This included recognising, making sense of and understanding experiences; knowing what to do; and the importance of the parent and caregiving role. These findings appear in line with carer coping models such as the transactional stress coping model, which emphasises that an individual's appraisal of a situation may mediate stress levels (Lazarus & Folkman, 1984), and the double ABCX model (McCubbin & Paterson, 1983), which suggests the single most important predictor of parental stress was the negative definition of the situation (Saloviita, Itälinna and Leinonen, 2003).

Influence of sociocultural and socioeconomic context. Some studies (e.g. Hatton et al., 2010; Hatton et al., 2003; Collins & Coughlan, 2016; and Reilly et al., 2010) reported findings regarding the influence of the sociocultural and socioeconomic context on parents. This included ethnicity, racism, discrimination, language, family context, and parent relationship status. These findings may be explained by ecological systems theory (Bronfenbrenner, 1979), specifically the impact of wider systems on parents and the family, such as the macrosystem, which includes social and cultural values. Existing research supports this notion, with reports that people with intellectual disabilities continue to be misunderstood and stigmatised (Inglis and Swain 2012); the single important predictor of stress for fathers being the experienced social acceptance of

the child (Saloviita, Itälinna and Leinonen, 2003); and over a third of carers reporting financial difficulties (ASCSTHSC Information Centre, 2017).

Parent Role and Identity Studies

Six parent role and identity studies included papers focusing on the experiences of fathers (Boström & Broberg, 2014; Davys et al., 2017b); working alongside caring (Chou & Kröger, 2014; Chou et al., 2013); support needs of caregivers (Sandy, Kgole, & Mavundla, 2013); and the cultural context of caring (Heer, Larkin, Burgess & Rose 2012).

Difficulties of parenting and sacrifices made. Similar to the health-related studies, almost all the studies exploring parent role and identity referred to the demands of the role of being a parent of a child with an intellectual disability and the associated emotional impact, including shock (Davys et al., 2017b), frustration (Sandy et al., 2013) and anger (Heer et al., 2012). In terms of differences between these studies, only one study (Sandy et al., 2013) reported positive experiences of parenting children with intellectual disabilities, in terms of the role being rewarding as well as difficult. Willingham-Storr (2014) identified that parenting a child with an intellectual disability is not always a negative role; it is a role that parents find both rewarding and empowering. Sandy et al. (2013) also reported the impact of stigma, referring to discrimination and social exclusion experienced by parents of children with intellectual disabilities living in South Africa.

Parent coping. Some studies referred to parents coping as individuals, particularly activities parents do to maintain their wellbeing such as leisure, practicing religion, and work (Davys et al., 2017b; Chou & Kröger, 2014; Chou, Fu & Chang,

2013). These findings could be considered in relation to the role of parental emotional resources in explaining parents' coping resources (Al-Yagon, 2015).

Importance of knowledge, understanding, predictability and certainty. Another evident theme in the parent role and identity studies was regarding parents' concern for the future which included anxiety and worry of what might happen, dealing with uncertainty, and the sense of parents needing to be sure of, understand and make sense of things (Boström & Broberg, 2014; Davys et al., 2017b; Heer et al., 2012). This theme highlights the importance of locus of control for parents of children with intellectual disabilities (Hassall et al., 2005).

Importance of external support. Similar to health-related studies, many parent role and identity studies identified the importance of external support (Davys et al., 2017b; Chou & Kröger, 2014, Chou et al., 2013; Sandy et al., 2013; Heer et al., 2012). Findings indicated that services could communicate clearer, be more responsive and attentive, as well as provide more practical support such as financial help, training, information, and advice. External support was also valued in terms of informal support, such as family and social networking. These findings reflect the literature in this area regarding the stress and tension parents experience due to insufficient and unreliable support services, with large numbers of parents left feeling unsupported (Griffith et al., 2011; Mencap, 2007; McConkey et al., 2004; Hatton et al., 2016).

Lifespan-Related Studies

Four lifespan-related studies included papers focusing on pre-school children with intellectual disabilities (Olsson & Roll-Pettersson, 2012; Agbenyega & Tamakloe, 2014); sex and relationships (Pownall, Jahoda, Hastings, & Kerr, 2011); and transition and independence (Docherty & Reid, 2009).

The importance of the role of parents. These studies demonstrated the importance of the role of parents across different life stages. Parents were described as gatekeepers and facilitators (Docherty & Reid, 2009); negotiators (Agbenyega & Tamakloe, 2014); orchestrators and coordinators (Olsson & Roll-Pettersson, 2012); and seen as information-gatherers (Pownall et al., 2011). This theme is consistent with literature emphasising that, in addition to care demands, carers are key organisers of support services and often advocate on behalf of their family members (Weiss & Lunsky 2010; Griffith et al., 2011).

The importance of information to parents. Similar to the 'knowledge, understanding, predictability and certainty' theme, lifespan-related studies referred to the importance of information for parents. This included information about their child (Olsson & Roll-Pettersson, 2012); school options (Agbenyega & Tamakloe, 2014); sex and relationships (Pownall et al., 2011) and transition to adulthood, such as identifying the next stages of development and parents knowing what their child will be doing (Docherty & Reid, 2009). These findings relate to previous research stating over a third of carers reported it was difficult to find information and advice (ASCSTHSC Information Centre, 2017) and that levels of parent stress are affected by levels of formal and informal support (Hassall et al., 2005). The importance of information, knowing, predictability and certainty may also link to literature on parent coping styles, and that having information is associated with some coping and approach styles. Some parents have more effective coping strategies than others. Differences between parents may be understood in terms of the transactional stress coping model, which emphasises an individual's appraisal of a situation may mediate stress levels (Lazarus & Folkman, 1984).

The emotional impact of parenting a child with an intellectual disability. Similar to health-related and parent role and identity studies which highlight difficulties of parenting children with intellectual disabilities, lifespan-related studies noted the emotional impact of being a parent across different life stages. This included feelings of stress, hurt, distrust, apprehension, and fear (Agbenyega & Tamakloe, 2014; Pownall et al., 2011). These findings appear in line with the existing literature regarding increased parenting stress (Hassall et al., 2005; Dyson, 2003) and parental emotional resources and coping (Al-Yagon, 2015). For example, parents who appraise transition to adulthood as stressful may have more negative experiences than parents who appraise the situation as rewarding (Biswas, Tickle, Golijani-Moghaddam, & Almack, 2017).

Independence, choice and control. This theme concerned parents' thoughts and feelings regarding their child's independence, making choices, power and control. This included parents' concerns regarding who makes choices, who is in control, and how their child copes with less support or without support. These findings support research emphasising the significance of locus of control to parenting stress (Hassall et al., 2005). Additionally, parent and family expectations may shift over time, with parents wanting to facilitate their child's adult identity and independence. This may be likely in countries with higher income when considering developing social narratives around disability and that people with disabilities in the UK are more integrated in communities. One difference noted between the lifespan-related studies is that studies of parents with younger children were more focused on how to gather enough information and the stress of making the right choices for their child (e.g. Agbenyega & Tamakloe, 2014) whereas studies on parents with young adult children were more focused on how much responsibility, choice, and control to allow the child and the stress, fear, and apprehension relating to this (e.g. Pownall et al., 2011; Docherty & Reid, 2009). Age-related

differences may be explained by lifespan theories considering which stages parents view their child compared with the stages parents would like their child to be, for example 'independent' or 'self-sufficient', and the resulting struggle associated with this.

Summary of Findings

Four concepts were evident across the three categories: the difficulties of parenting a child with an intellectual disability; support from others; parent coping and self-care; and knowledge, certainty and control.

The difficulties of parenting a child with an intellectual disability. This concept encapsulates the emotional impact on parents as well as sacrifices parents often make and the responsibilities many have. Difficulties of parenting also includes wider sociocultural factors, such as social stigma, discrimination, racism, and the family context. This signals the importance of wider systems in offering emotional and practical support to parents to reduce parent demands as well as stigma and discrimination.

Support from others. This concept represents the importance of external support, both formal and informal. In many studies parents reported the value of family support and social networking. Additionally, parents reported a lack of support from services and professionals, specifically regarding communication, attentiveness, openness, consistency, promptness, and a lack of practical support such as information, advice, training and financial support.

Parent coping and self-care. This concept includes findings across the studies that highlighted the importance of parents coping as individuals. This is associated with parents recognising, understanding and acting on particular issues; appraisal of their role as parent to a child with an intellectual disability; and the day-to-day activities parents

reported regarding self-care and maintaining wellbeing, such as work, leisure and practicing religion.

Knowledge, certainty and control. This final concept reflects a wider group of themes evident across the categories regarding the importance of parents: knowing information; being able to understand and make sense of things; feeling more certain about or being able to predict better what the future holds; and feeling more in control in terms of their own lives and what is happening with regards to their child. Undoubtedly this concept links to the other concepts, in that lack of knowledge, certainty, and control constitutes a significant difficulty for parents, it has an impact on coping and it is impacted by external support.

Quality Appraisal

This quality appraisal outlines a range of strengths and limitations to the studies included in the current review using the checklist (Appendix B) based on criterion from the CASP (Public Health Resource Unit, 2006) with additional items from well-established guidelines for qualitative studies (Yardley, 2000, 2008, 2017; see Appendix D). Twelve topics were rated as 'strong', 'mixed' or 'weak' for each of the twenty studies: research question; design; sampling; data collection; reflexivity; ethical issues; sensitivity to context; commitment and rigour; transparency and coherence; data analysis; findings; and impact and importance. Each topic and each study was given an overall rating based on numbers of 'strong', 'mixed' and 'weak' ratings along with the researcher's opinion on the study or topic in its entirety. Ratings are presented in Table 3. Although not validated, these ratings are based on published guidelines and provide an indication of overall quality and rigour for evaluation.

Table 3.

Study quality appraisal ratings

	Research Question	Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Data Analysis	Findings	Impact and Importance	Overall Researcher Rating
Agbenyega & Tamakloe (2014)	Strong	Mixed	Mixed	Strong	Weak	Mixed	Strong	Mixed	Strong	Mixed	Mixed	Strong	Mixed
Barr & McConkey (2007)	Strong	Strong	Mixed	Strong	Mixed	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Strong
Boström & Broberg (2014)	Strong	Strong	Strong	Strong	Mixed	Mixed	Strong	Strong	Mixed	Mixed	Strong	Mixed	Strong
Chou, Fu & Chang (2013)	Strong	Mixed	Mixed	Strong	Mixed	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Chou & Kröger (2014)	Strong	Mixed	Mixed	Strong	Weak	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Mixed
Clarke et al. (2007)	Strong	Strong	Mixed	Strong	Strong	Strong	Weak	Mixed	Strong	Mixed	Strong	Strong	Mixed
Collins & Coughlan (2016)	Strong	Weak	Mixed	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong	Strong	Strong
Davys, Mitchell & Martin (2017b)	Strong	Strong	Strong	Strong	Weak	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Docherty & Reid (2009)	Strong	Mixed	Mixed	Strong	Mixed	Strong	Mixed	Mixed	Mixed	Strong	Strong	Strong	Mixed
Elford, Beail, & Clarke (2010)	Strong	Strong	Strong	Strong	Weak	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Faust & Scior (2008)	Strong	Mixed	Mixed	Strong	Weak	Weak	Mixed	Strong	Strong	Mixed	Strong	Strong	Mixed
Hatton et al. (2003)	Strong	Mixed	Weak	Strong	Weak	Mixed	Mixed	Strong	Strong	Mixed	Strong	Strong	Mixed
Hatton et al. (2010)	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong	Strong	Strong	Strong	Mixed	Strong
Heer et al. (2012)	Strong	Strong	Mixed	Strong	Weak	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
James (2016)	Strong	Strong	Strong	Strong	Weak	Mixed	Strong	Strong	Mixed	Mixed	Strong	Strong	Mixed
Olsson & Roll-Pettersson (2012)	Strong	Strong	Strong	Strong	Mixed	Mixed	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Pownall et al. (2011)	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Reilly et al. (2008)	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong
Reilly et al. (2010)	Strong	Strong	Strong	Strong	Mixed	Strong	Strong	Strong	Mixed	Mixed	Strong	Strong	Strong
Sandy, Kgole, & Mavundla (2013)	Strong	Weak	Mixed	Strong	Weak	Strong	Mixed	Mixed	Mixed	Mixed	Mixed	Strong	Mixed
Overall Researcher Rating	Strong	Mixed	Mixed	Strong	Weak	Mixed	Strong	Strong	Strong	Mixed	Strong	Strong	

Research Question

All twenty papers clearly stated the relevance and importance of research into a novel topic area. Aims and objectives were generally clearly stated.

Design

All papers clearly stated their use of a qualitative method and specified this as IPA. However, two studies (Collins & Coughlan, 2016; and Sandy et al., 2013) did not provide any rationale or justification of using a qualitative approach or for selecting IPA as a suitable method. Six studies (Agbenyega & Tamakloe, 2014; Chou et al., 2013; Chou & Kröger, 2014; Docherty & Reid, 2009; Faust & Scior, 2008; and Hatton et al., 2003) briefly mentioned using a qualitative method and often provided a description of IPA but without a clear rationale.

Sampling Strategy

All but one of the papers (Collins & Coughlan, 2016) clearly described how participants were selected. Parents of children with intellectual disabilities are by nature a homogenous sample, and most studies alluded to the importance of homogeneity when using an IPA approach. Homogeneity was improved further through the study of specific populations such as parents of children with intellectual disabilities going to kindergarten (Agbenyega & Tamakloe, 2014) or parents who have experienced the death of a child with an intellectual disability (Reilly et al., 2008; and Reilly et al., 2010).

One paper (Hatton et al., 2003) included twenty-six parents and three papers (Barr & McConkey, 2007; Chou et al., 2013; and Faust & Scior, 2008) included between fourteen and nineteen parents. These sample sizes may be considered too large for an IPA study. Although experts Smith et al. (2009) acknowledge “there is no right answer to the question of the sample size” they state that “IPA studies usually benefit from a

concentrated focus on a small number of cases" (p.51). Only eight papers provided a clear inclusion and exclusion criteria. Seven papers did not provide any inclusion and exclusion criteria (Agbenyega & Tamakloe, 2014; Barr & McConkey, 2007; Chou & Kröger, 2014; Clarke et al., 2007; Faust & Scior, 2008; Heer et al., 2012; and Sandy et al., 2013). Five papers provided an inclusion and exclusion criteria which lacked specificity (Davys et al., 2017b; Docherty & Reid, 2009; Hatton et al., 2010; Pownall et al., 2011; and Reilly et al., 2010).

Data Collection

All papers provided a clear justification for and explanation of the study setting, methods of data collection chosen, and the procedure involved in data collection. Clarke et al. (2007) was rated as 'strong' overall although more information could have been provided about how decisions were made regarding the research process and procedures, and whether any modifications were made.

Reflexivity

Reflexivity was the only item rated as 'weak' overall across the twenty papers. Finlay (2002) emphasised the importance of reflexivity in qualitative research, that is, the necessity for researchers to engage in explicit, self-aware analysis of their own role and acknowledge how this may influence the interpretation of participant accounts. More recently, Gough (2017) described reflexivity as an imperative part of the qualitative research process, and not something to be removed for the sake of word count.

Nine papers did not evidence researcher reflexivity (Agbenyega & Tamakloe, 2014; Chou & Kröger, 2014; Davys, et al., 2017b; Elford et al., 2010; Faust & Scior, 2008; Hatton et al., 2003; Heer et al., 2012; James, 2016; and Sandy et al., 2013). Nine papers demonstrated reflexivity at only one stage of the research process, either through

documenting use of supervision or a reflective log (Barr & McConkey, 2007; Boström & Broberg, 2014; Chou et al., 2013; Docherty & Reid, 2009; Hatton et al., 2010; Olsson & Roll-Pettersson, 2012; Pownall et al., 2011; Reilly et al., 2008; and Reilly et al., 2010).

Only one paper (Collins & Coughlan, 2016) demonstrated reflexivity clearly throughout the process, including the use of bracketing, a method used in qualitative research to mitigate the potentially deleterious effects of preconceptions that may taint the research process, and has been emphasised as an important part of reflexivity (Tufford & Newman, 2010). As reflexivity was not acknowledged in many of the papers it was unclear to what extent findings were co-constructed between researchers and participants. Furthermore, there did not appear to be an increased demonstration of reflexivity in papers published recently compared with papers published before 2010, indicating that, despite reflexivity being highlighted as important, it is not being sufficiently reported.

Ethical Issues

All papers demonstrated integrity and respect for participants. However, a significant concern was that five papers did not explicitly report ethical committee approval (Agbenyega & Tamakloe, 2014; Boström & Broberg, 2014; Faust & Scior, 2008; Hatton et al., 2003; and Olsson & Roll-Pettersson, 2012). Some papers lacked detail of how ethical issues were addressed, particularly how confidentiality and sensitive issues were managed (Faust & Scior, 2008; Hatton et al., 2010; and James, 2016).

Sensitivity to Context

Fifteen papers were rated ‘strong’ with regards to sensitivity to context. Findings tended to be strongly grounded in the data, with use of verbatim quotes to support themes, and themes were generally well linked to literature. Four papers lacked a clear rationale for selecting a qualitative or IPA methodology (Docherty & Reid, 2009; Faust &

Scior, 2008; Hatton et al., 2003; and Sandy et al., 2013). Clarke et al. (2007) did not use verbatim quotes which was a significant weakness of this paper. Sandy et al. (2013) did use verbatim quotes, however it was not clear how representative the quotes were of the overall sample due to only referencing participants as males and females.

Commitment and Rigour

Fifteen studies were rated 'strong' with regards to commitment and rigour. These studies demonstrated high attentiveness to participants during data collection, selected an appropriate and reasonably homogenous sample, drew quotes evenly across participants, demonstrated credibility and validity checks, and referred to use of supervision during the research. Some papers could have referenced more use of supervision and descriptions regarding how decisions and conclusions were made (e.g. Hatton et al., 2003; and James, 2016); provided more information regarding credibility and validity checks (Heer et al., 2012); and been clearer which father or mother was referred to in verbatim quotes to help the reader see links across individuals and couples, and to ensure quotes were evenly drawn from different participants (Reilly et al., 2010).

Five papers were rated as 'mixed' due to lack of verbatim quotes (Clarke et al., 2007); being unclear whether verbatim quotes were drawn evenly across participants (Collins & Coughlan, 2016; and Sandy et al., 2013); lack of information regarding supervision and/or credibility checks (Agbenyega & Tamakloe, 2014; Collins & Coughlan, 2016; Docherty & Reid, 2009; and Sandy et al., 2013); and information about the sample not being presented clearly (Docherty & Reid, 2009).

Transparency and Coherence

Fifteen studies were rated 'strong' with regards to transparency and coherence. These studies reported clearly how participants were selected; how interviews were

constructed and conducted; how analyses were carried out, including examples; consistently followed IPA principles; explored ambiguities and contradictions in the data; and powerfully presented an argument(s). Some studies could have improved further on this topic by providing: more information about how the interview schedule was produced (Agbenyega & Tamakloe, 2014; Davys et al., 2017b;), example questions (Chou & Kröger, 2014; Sandy et al., 2013), more example quotes from participants for themes (Sandy et al., 2013), and a visual representation of the findings (Davys et al., 2017b, Elford et al., 2010, Hatton et al., 2003, Olsson & Roll-Pettersson, 2012; Pownall et al., 2011; Reilly et al., 2008; Sandy et al., 2013).

Four papers were rated 'mixed' due to studies lacking information about how participants were selected (Boström & Broberg, 2014) or how interviews were constructed or conducted (Docherty & Reid, 2009; James, 2016; Reilly et al., 2010) and a lack of visual representation of data (Boström & Broberg, 2014; Docherty & Reid, 2009; Reilly et al., 2010).

Data Analysis

Most studies described data analysis clearly with good use of data and quotes to support themes and findings. Some studies could have described data analysis clearer, for example by using a table or diagram and listing results according to themes (Agbenyega & Tamakloe, 2014; Hatton et al., 2003; Docherty & Reid, 2009). Sandy et al. (2013) would have benefitted from more examples to support the researchers' interpretations and findings, and there was no consideration of alternative explanations or analysis.

The main criticism, and reason for sixteen studies being rated 'mixed' in terms of data analysis, was a lack of reflexivity. Sixteen studies did not provide evidence of the researchers examining their own role potential bias and influence during analysis and

selection of data presentation. Of the studies that did mention reflexivity in data analysis (e.g. Docherty & Reid, 2009, Hatton et al., 2010) more consideration of this, and across multiple sections of the papers, would have been welcomed.

Findings

The reporting of findings was a relative strength across the studies. Eighteen studies were rated 'strong' for this topic, meaning that findings were explicit with adequate discussion of evidence for and against the researcher's argument in relation to the research question(s), including discussion of the credibility of the findings. Some studies could have improved the reporting of findings with more discussion with regards to evidence for and against the researchers' arguments (Agbenyega & Tamakloe, 2014; Sandy et al., 2013; Chou & Kröger, 2014; Davys et al., 2017b).

Impact and Importance

Eighteen studies described a clear impact of some interesting and useful findings with research and clinical implications outlined. Three of the studies rated 'strong' could be improved further in this topic with regards to some research implications and suggestions (Chou & Kröger, 2014; Davys et al., 2017b; and Sandy et al., 2013) whilst Docherty & Reid (2009) lacked detail in terms of clinical and practical implications.

Two studies were rated 'mixed' due to a lack of evidence of how findings may be transferred to other populations and new areas of research that may be necessary following this (Boström & Broberg, 2014) and specific clinical, practical or research implications or suggestions (Hatton et al., 2010).

Summary

In summary, studies showed strengths in most areas of methodological rigour key to IPA quality, with twelve of the twenty studies rated as 'strong' overall. Overall, areas

requiring more focus and improvement in future research using IPA with parents of children with intellectual disabilities are evidencing reflexivity, expanding on ethical considerations, justifying research design, and using explicit inclusion and exclusion criteria in participant sampling.

Discussion

The current review aimed to systematically identify, synthesise and evaluate the quality of research using IPA to explore the experiences of parents of children with intellectual disabilities. Evaluation of the quality of research revealed a range of methodological strengths and limitations of the studies. Most of the studies and topics were rated as 'strong' overall. None of the studies were rated 'weak' overall. Only one topic, reflexivity, was rated 'weak' overall.

The data synthesis revealed four concepts regarding similarities identified both within and between the three categories of studies reviewed. Many parents reported significant difficulties, emotionally and practically, of parenting a child with an intellectual disability. Specifically, parents reported struggling with lack of knowledge, certainty and control, both related to their own identity and role as parents, and related to their child's health, education, age or sexuality. Studies reported the importance of parents coping as individuals, which included appraisal of their role of being a parent and the strategies and activities for self-care and maintaining wellbeing, as well as the importance, and often lack of, external support, such as family support, social networking, services and professionals. The findings have a variety of implications for clinical practice, policy and research which are highlighted below.

Clinical and Policy Implications

Given that parents of children with intellectual disabilities are significantly more likely to experience parenting stress than parents of children without intellectual disabilities (Hassall et al., 2005; Dyson, 2003), there is a strong rationale for clinicians to address the psychological and emotional needs of parents of children with intellectual disabilities. Interventions may firstly address some of the emotional impact related to difficulties of parenting, including the impact of stigma. Secondly, interventions may teach skills to support parents with self-care and coping, including the importance of cognitive appraisals of the parent role. Finally, interventions could address the importance of knowledge, certainty and control for parents, particularly providing parents with information and resources at key times such as post-diagnosis and transition to adulthood, as well as support for parents in tolerating uncertainty.

Clinical Psychologists are well placed to support in facilitating interventions, offering training and supervision for other professionals working with parents, and empowering third sector support. Family-support interventions have been found to benefit participants' well-being and improve service access and satisfaction (Heller, Gibbons & Fisher, 2015). The strongest evidence base is for cognitive behavioural group interventions, especially for the reduction of stress in mothers (Hastings and Beck, 2004). Community mindfulness-based programs can also be an effective intervention to reduce stress and improve psychological well-being for parents and caregivers of children with developmental disabilities (Bazzano et al., 2013). Furthermore, in light of the finding that perceived stigma impedes access to supports, identification of caregivers who may be more susceptible to stigma is vital (Cantwell, Muldoon, and Gallagher, 2015). Providing parents with methods for dealing with perceived stigma and highlighting the importance of attending support groups for emotional support may mitigate some of the negative

consequences of stigma, such as the impact on coping and support (Cantwell et al., 2015). Practitioners may need to employ anti-stigma and anxiety reduction strategies in promoting better mental health and to explore cultural elements that can be tapped on for better coping (Chiu, Yang, Wong & Li, 2015).

In addition to psychological support and interventions, the current review, alongside existing literature, recommends increasing practical support for parents of children with intellectual disabilities, thus reducing existing stressors and demands. In the UK, examples of practical support for parents are recommended in the NICE guidelines for mental health problems in people with learning disabilities (NICE, 2018a) and behaviour that challenges (NICE, 2018b). This includes carer assessments; short breaks and other respite care; family advocacy; family support and information groups; disability-specific groups; and skills training and emotional support. Parents with an identified mental health problem should be offered interventions in line with recommendations or a referral to a mental health professional who can provide interventions (NICE, 2018a; NICE, 2018b). Research suggests that standard service models, such as respite care and case management reduce parental stress (Hastings & Beck, 2004). However, White and Hastings (2004) found accessing professional and service support was associated with the child's needs rather than parents' needs. Services may also support parents by reviewing families' financial situation and providing additional financial support where appropriate, with parenting stress reduced in parents who were not experiencing financial hardship (Meppelder, Hodes & Schuengel, 2015).

Increased joint working between adult health and social care would support parents of children with intellectual disabilities. Currently, many people receive fragmented care built around priorities or targets of services, rather than people's needs, partly due to ongoing challenges around staffing and recruitment of care services (Care

Quality Commission (CQC), 2017). Collaboration needs to happen not just between sectors, but between local agencies and care professionals too, and this needs to happen with more consistency and urgency and be supported by national leaders (CQC, 2017).

Furthermore, there may be a rationale for increasing levels of informal support by working with couples, families, and social networks more systemically in families of children with an intellectual disability. Research has highlighted that increased help and emotional support from informal sources, such as a spouse, extended family and friends is associated with parent well-being (White & Hastings, 2004) and higher family quality of life (Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014), whilst large support networks were also shown to decrease the association between child behaviour problems and child-related parenting stress (Meppelder et al., 2015). This may reflect a role for statutory services in organising and supporting self-advocacy groups and parent-led services, with data indicating the value of parent-led support networks (Hastings & Beck, 2004). However, a recent study reported that, although informal social support appears to be important to parents and may help alleviate burden, it does not appear to act as a moderator as anticipated (Robinson, Weiss, Lunsky, and Ouellette-Kuntz, 2016).

A wider implication of the current review is the importance of reducing social stigma for people with intellectual disabilities and their parents and carers, given that parents expressing negative family experiences were due to feeling stigmatised (Lalvani, 2015). It is important to increase knowledge and awareness, and reduce stigma in the community, as a deeper knowledge and more positive community attitudes may reduce family internalised stigma (Werner & Sculman, 2015). Interventions to reduce stigma should include attempts to reduce public stigma, particularly among specific communities, such as certain ethnic communities, and to support individuals with intellectual disabilities from particular communities in reporting higher levels of stigma

(Ali et al., 2014). Mango, Davis and Goar (2017) highlighted the role of challenging rather than deflecting stigma, which places the burden of embarrassment, discomfort, and inconvenience on those people and institutions that enact stigmatisation and empowering parents of children with disabilities to push back. This often means confronting strangers, friends, business owners, and legislators who perhaps unknowingly perpetuate prejudice and social exclusion.

Research Implications

The current review highlights recommendations for future research both in terms of the quality of IPA research with parents of children with intellectual disabilities, and aspects of parenting that could be explored further. In terms of the former, the areas requiring more focus and improvement are evidencing reflexivity, ethical considerations, justification of research design, and use of an inclusion and exclusion criteria in participant sampling. Concerning reflexivity, researchers are encouraged to view the explicit and self-aware analysis of their own role, and how this may influence the interpretation of participant accounts, as an imperative part of the qualitative research process, and not something to be removed for the sake of word count (Gough, 2017). Reflexivity may be evidenced by reference to reflective logs, bracketing interviews, and supervision, and these should be reported and reflected on throughout the research process. Regarding ethical considerations, papers must explicitly state ethical committee approval and provide sufficient detail regarding how ethical issues were addressed. The integrity and respect for participants was often clear with reference to informed consent. However, further information regarding how participant confidentiality and sensitive issues are managed would be welcomed. In terms of research design, researchers are encouraged to report a clear rationale to justify a qualitative approach and for selecting IPA as a suitable qualitative method. Finally, with regards to reporting samples, a clear

inclusion and exclusion criteria should be reported, for example presented in a table. Papers should also report whether children have a diagnosis of intellectual disability; some papers were ruled out of the current review due to a lack of clarity regarding this. Papers should be clearly titled with reference to the sample studied; papers were identified during the search which referred to parents of children with intellectual disabilities when parents of children with other diagnoses and without an intellectual disability were also included. Furthermore, information regarding parents and children, such as ethnicity, age, gender, and other physical and mental health diagnoses of the children should be reported and presented clearly, ideally in a table.

Regarding future lines of inquiry, similar to research recommendations in other reviews (Fishwick, 2009; Willingham-Storr, 2014), further studies would be welcomed which aim to understand the experiences of fathers of children with intellectual disabilities as well as older parents of older children with intellectual disabilities. In terms of IPA research, over half of the studies in the current review were carried out in the UK, and future studies could employ this approach to explore experiences of parents across a variety of countries and cultures. For example, the influence and impact of stigma across cultures could be explored further as well as parental experiences of interventions to reduce stigma. In some specific topic areas where IPA has been used effectively to deepen understanding regarding the experiences of parents, in turn generating hypotheses to be explored further, researchers may wish to consider using self-report measures with larger samples of parents and analyse data using quantitative or mixed methods approaches. Finally, the research agenda could be expanded to consider the adaptation of families caring for children with intellectual disabilities through greater understanding of the social-ecological constraints on families and the resources needed to meet the 'normal', everyday adaptive challenges they face (McConnell & Savage, 2015).

Limitations of the Review

A significant limitation of the current review is that included studies were predominantly conducted in Europe, with over half carried out in the UK. Furthermore, most studies included parents of children or young adults with intellectual disabilities, and therefore there is a lack of representation of the experiences of older parents with older adult children with intellectual disabilities. With exception of the gender-specific studies, many of the studies recruited more mothers than fathers, although more recently some studies have specifically focused on experiences of fathers of children with intellectual disabilities. Several other IPA studies could have been included but it was unclear if all the children had a diagnosis of intellectual disability. Terms such as 'developmental disability' were often used as an umbrella term for people with diagnoses of intellectual disability, learning difficulties, Autism Spectrum Disorder, and Attention Deficit Hyperactivity Disorder. Finally, the current review may be limited by exclusion of the grey literature, which means informative unpublished data is not represented.

Conclusions

The current review has systematically identified, synthesised and evaluated the quality of research using IPA to explore experiences of parents of children with intellectual disabilities. Findings unilaterally indicate that parents experience a range of difficult emotions and practical difficulties, and that the level of parent coping and external support received have an important influence. It is hoped the findings of the current review can be used to influence future high-quality IPA research exploring the experiences of parents of children with intellectual disabilities, with increased researcher reflexivity.

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Conflicts of Interest

No conflicts of interest have been declared.

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Oxford Institute of Clinical Psychology Training

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Paper B

Having a child with an intellectual disability transition to adulthood:

A parental perspective.

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Abstract

Background: Transition to adulthood is an important time for young people and may be a particularly challenging time for people with intellectual disabilities. However, there has been little research in the UK regarding the experiences of parents who have a child with an intellectual disability transitioning to adulthood.

Method: The study used Interpretive Phenomenological Analysis to explore the lived experiences of ten parents who had a child (aged 18-25 years) with an intellectual disability.

Results: Three superordinate themes were generated from the data: 1) Transition: The good, the bad and the unknown; 2) Striving for independence; and 3) Supporting the supporters. Parents experienced many difficulties and uncertainty related to their role, their child's independence, navigating services for their child, and accessing support for themselves.

Conclusions: Increased collaboration and consistency from statutory services is required in addition to providing emotional support to parents and facilitating parent support networks.

Keywords: Interpretative Phenomenological Analysis; interview; parent; intellectual disability; learning disability; lived experience; transition

Proposed Journal: Journal of Applied Research in Intellectual Disability (See Appendix E for author guidelines)

Accessible Summary

- Growing up and becoming an adult can be a difficult time, especially for people with intellectual disabilities and their families.
- We wanted to find out what it is like for parents who have a child with an intellectual disability when their child is growing up and becoming an adult. Ten parents were interviewed. They were asked questions about what it is like being in their family, helping their child, support services for their child, and support services for parents.
- From our conversations, we made a list of things that mattered the most to parents:
    1) Good things and bad things happened while their child was growing up. Many parents were confused about what to do when their child turned eighteen years old. They were worried about what would happen in the future.
    2) Children's independence was really important to parents. They found it hard sometimes helping their child to be more independent and talk about adult topics like sex, relationships and moving out.
    3) Getting more help and talking to other parents who have children with an intellectual disability.
- We have learned some new things about parents who have a child with an intellectual disability from these findings. Staff who work with people with intellectual disabilities and their families can read this study. It might give them ideas about ways they can help, like:
    1) Working together in a better way to help parents who have a child with an intellectual disability becoming an adult.

2) Setting up support groups for parents to talk to one another and learn from each other.
3) Writing better plans with every person with an intellectual disability. This will help young adults and their parents understand better what happens when you become an adult and who can help.

Having a child with an intellectual disability transition to adulthood:

A parental perspective

People with Intellectual Disabilities

People with intellectual disabilities comprise approximately 2% of the UK population or about 1.5 million people (Hatton, Glover, Emerson, & Brown, 2016; Mental Health Foundation, 2018). The term intellectual disability indicates developmental difficulties in intellectual and adaptive functioning present before adulthood (British Psychological Society 2015; American Psychiatric Association 2013; see Appendix F). People with intellectual disabilities have increased rates of co-morbid physical and mental health problems (Cooper et al., 2015). A social movement in the UK over the last forty years, reinforced by the Valuing People white paper (Department of Health, 2001), has seen people with intellectual disabilities move out of long stay institutions and integrate into communities, with many people living in their own homes. Subsequently, transition to adulthood for young people with intellectual disabilities now involves very different processes and outcomes compared to the times of institutions.

Transition to Adulthood

Transition to adulthood is "the process of moving from the protected life of a child to the autonomous and independent life of an adult" (Leonard et al., 2016). It is a period of exploration and experimentation involving physical, sexual, social and psychological change. This may be a challenging time for young people as they adapt to new social roles, seek to develop their own identity in relation to others, and plan for the future (Salt, 2017; Wendelborg & Kvello, 2010). These activities correspond to lifespan models, such as Havighurst's (1972) description of 'adolescence' and 'early adulthood', and Carter & McGoldrick's (1989) description of 'families with adolescents' and

'launching children and moving on' (see Appendix G for consideration of lifespan models for people with intellectual disabilities). The term transition is used in this paper when referring to transition to adulthood. This includes multiple components relating to developmental stages as well as transitioning through services.

The challenges of transition may be compounded for people with intellectual disabilities (Task Force, 2009). Compared to youth without disability, transition is characterised by wider scope, longer duration, and attenuated experiences (Hudson, 2003), particularly for those belonging to minority ethnic groups (Hussain, Atkin & Ahmed, 2002). Young people with intellectual disabilities ruminate significantly more during transition and are more distressed by their worries than their non-disabled peers, whilst families attempt to navigate complex pathways and confusing systems (Forte, Jahoda & Dagnan, 2011).

In the UK, transition planning and care is recommended for young people up to twenty-five years old who have mental health problems, are disabled, or are looked after by social care services (NICE, 2016). However, there is a dearth of UK-based research focusing on transition experiences of young people with intellectual disabilities and their families. This contrasts with other countries where research about transition has included parents in Australia (e.g. Leonard et al., 2016), USA (e.g. Blustein, Carter & McMillan, 2016), Canada (e.g. Schneider & Hattie, 2016), Hong Kong (e.g. Pin et al., 2016), and the Netherlands (e.g. van Heumen & Schippers, 2016). NICE (2016) has recommended research regarding transition for young people with and without intellectual disabilities.

Parental Experiences of Having a Child with an Intellectual Disability

There is a long tradition of research involving family carers of people with intellectual disabilities (Ramcharan & Grant, 2001). In the UK, over 40% of adults with

intellectual disabilities live with family or friends who care for them (Hatton et al., 2016). Family members, particularly mothers, provide the most support to their child with an intellectual disability (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006). In the current study, the term 'parent' refers to the person who undertakes primary parental and caregiving responsibility for the person with an intellectual disability. This is often mothers and fathers but may extend to other family, and adoptive or foster parents.

Research into parental experiences and needs in relation to having a child with an intellectual disability is important. Families play a key role in caregiving for individuals with intellectual disabilities across their lifespan, many of whom continue to live in the family home well into their middle age (Todd, Shearn, Beyer, & Felce, 1993; McConkey 2005). However, research into parents' experiences of raising a child with an intellectual disability is varied, with themes of stress and burden reported alongside more positive experiences (Griffith & Hastings, 2014). Many carers report that managing the daily care needs of family members with intellectual disability is tiring and stressful (Todd et al., 1993). In addition to specific care demands, carers are key organisers of support services and often advocate on behalf of their family members (Griffith et al., 2011). Parents are significantly more likely to experience parenting stress than parents of children without an intellectual disability (Hassall, Rose & McDonald, 2005) and report experiencing stress and tension due to insufficient and unreliable support services (Griffith et al., 2011). Levels of parent stress are affected by levels of formal support from professionals and social support from partners, family members and friends (Hassall et al., 2005). Despite these challenges, parents report positive experiences of raising a child with an intellectual disability (Beighton & Wills, 2017; Griffith & Hastings, 2014; Willingham-Storr, 2014). Thus, positive impact and life satisfaction may co-exist with increased likelihood of depression, poor quality of life, and significant caregiving burdens (Blacher, 2001).

Experiences of Parenting a Child with an Intellectual Disability during Transition

Although experiences of families with young children with intellectual disabilities have been widely discussed in the literature (Willingham-Storr, 2014; Kenny & McGilloway, 2007) less is known about experiences among families with transition-age children with intellectual disabilities (Boehm, Carter & Taylor, 2015). Transition is a time when other family situations are changing, siblings are moving out of home, and grandparents are ageing, sometimes requiring increased support themselves and potentially offering less informal support (Dyke, Bourke, Llewellyn, & Leonard, 2013). Some parents expressed concerns that as older children left home, they would lose one of their greatest sources of support (Todd & Jones, 2005).

Involvement of young people with intellectual disabilities and their parents during transition is critical for a successful transition experience (Kohler & Field, 2003; Kraemer, McIntyre, & Blacher, 2003). However, involvement is reported to be lacking (Beresford, 2004). One study found that some families reported uncertainty and stress; that topics covered in transition planning were often different from those they considered to be important; and that there was a lack of easily accessible information about what future possibilities might be (Heslop, Mallett, Simons & Ward, 2002). An Australian study found the three most helpful strategies indicated by parents that assisted with transition planning related to the provision of more information about financial assistance, the school transition program and the building of informal community-based supports (Leonard et al., 2016). Parents' concerns were about the capacity of their young adult adapting and changing to adult life; difficulty navigating services and programs; issues and challenges around their young person building connectedness; strain on family wellbeing and finances; and worry about the longer-term future (Leonard et al., 2016).

More than half of parents reported that the transition process had impacted on their daily life and wellbeing and, to a slightly lesser extent, on their families' wellbeing (Leonard et al., 2016). Similarly, Neece, Kraemer, and Blacher (2009) found that parents who were more satisfied with their child's transition had higher wellbeing than parents who were dissatisfied. Many parents were concerned about the long-term care of their young adult with the realisation that they could no longer be the main carer (Leonard et al., 2016). This realisation has been referred to as 'the second shock' by parents, paralleling transition with the initial diagnosis (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). Some parents feel their parenting role is extended indefinitely and want a life beyond parenting, yet they are prevented by the practicalities of daily caregiving (Todd & Shearn 1995). Research suggests a 'new' population of older people with intellectual disabilities due to improved survival and therefore an urgent need to develop services to assist families (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2012).

Given the paucity of research in this area, further studies are warranted to explore the experiences of parents who have a child with intellectual disability during transition.

Rationale for this Project

Interpretative Phenomenological Analysis (IPA) is a qualitative approach concerned with understanding participants' lived experiences and how they make sense of their experiences (Smith et al., 2009). This approach is well suited to under-researched groups (Smith et al., 2009) and has been increasingly used across cultures to explore experiences of parents of children with intellectual disabilities in areas including diagnosis (Boström, Broberg, & Hwang, 2010), sexual identity development (Wilkinson, Theodore, & Raczka, 2015), ageing (Iacano et al., 2016), and death (Reilly, Huws, Hastings & Vaughan, 2008). IPA includes a more 'interventionist' stance, where 'practitioners conducting research with groups can draw on their own professional

experience with clients to help them modify existing protocols when collecting data' (Smith et al. 2009, p.49). For more detail about IPA and the rationale for choosing this approach, see Appendix H.

To the author's knowledge, aside from studies by Wilkinson, Theodore and Raczka (2015) and Docherty and Reid (2009), which focused specifically on sexual identity and mothers of young adults with Down Syndrome respectively, there have been no UK-based studies that have used IPA to explore parental experiences of having a child with an intellectual disability transition to adulthood.

Aim

This study aimed to explore the experiences of parenting a child with an intellectual disability transitioning to adulthood and what meaning parents make of this.

Method

Design

This study employed an IPA methodology given its focus on lived experience. Semi-structured interviews were used to investigate the experiences of parents who have a child with an intellectual disability transitioning to adulthood.

Participants

In line with IPA methodology, purposive sampling was used to recruit ten parents of young adults with intellectual disabilities.

Inclusion criteria were:

- Parents of a young adult child (aged 18-25 years) with an intellectual disability.
- Parents lived with or had regular contact with their child between 13-18 years old.

Exclusion criteria were:

- Parents not being fluent in English.
- Parents who were the husband, wife or partner of another participant.

Recruitment

Contact was made with parents through local third sector organisations, statutory services and health and social care professionals supporting young adults with intellectual disabilities, although participants were not current users of NHS services. The researcher's existing connections with parents also provided a source of recruitment. Initially consent was obtained from potential participants to contact them. Parents were then emailed the participant information sheet (Appendix I) and telephoned to explain the nature and purpose of the study. If appropriate, an appointment was made to conduct the interview in a familiar private setting of participants' choice. All parents who contacted the researcher met the inclusion criteria for the study.

Measures

Demographic questionnaire. A demographic questionnaire (Appendix J) was administered prior to each interview to gather data on participant and child gender, ethnicity, age, religion, sexuality, and relationship status.

Learning Disabilities Screening Questionnaires (McKenzie & Paxton, 2006). The Learning Disability Screening Questionnaire (LDSQ; McKenzie & Paxton, 2006, see Appendix K) is a validated questionnaire used with individuals or family members to indicate if a person has an intellectual disability. This was administered to parents prior to interview. Parents were asked to comment on each question for their child. The LDSQ has seven items and each item is given a score of 1 or 0 points. The total score is calculated by simply adding up the number of points and is converted to a percentage

score. The higher the score, the less likely it is that the person has a learning disability. Parents confirmed that their child had an intellectual disability and the LDSQ was used as an indication of this and to consider the different levels of intellectual disability.

Semi-structured Interview Schedule. A semi-structured interview was developed following the process outlined by Smith et al. (2009) including open-ended questions with prompts to encourage parents to speak in-depth about their experiences (see Appendices L and M). The schedule was influenced by lifespan theories and consultations with young adults with intellectual disabilities, parents of people with intellectual disabilities and professionals in the field. A bracketing interview was conducted to elicit preconceptions which may influence the processes of data collection and analysis and to try to maintain an open and curious approach at this stage (see Appendix N). The interview schedule was piloted on two potential participants to check for question comprehension and to ensure questions elicited in-depth conversations about the experience of transition. The pilot interviews were used in the final analysis as no significant changes were made to the research procedure and interview schedule.

Data Collection

Interviews were conducted with ten parents between October 2017 and February 2018, audio recorded, and transcribed verbatim. Participants were reimbursed £20 for their time.

Ethical Considerations and Approval

Ethical approval was obtained from the Oxford Institute of Clinical Psychology Training (Appendix O) and Central University Research Ethics Committee at the University of Oxford (Appendix P). Service user input was sought on project materials such as the information sheet and interview schedule to ensure understanding.

All participants provided written informed consent (see Appendix Q). All data was stored and handled in accordance with the Data Protection Act (Great Britain, 1998). Pseudonyms were used, and any identifying information was changed or removed to protect participants' confidentiality. A debriefing sheet (Appendix R) was offered to all participants providing information and support available such as websites, carers groups and talking therapies. A full account of ethical considerations relating to the study is detailed in Appendix S.

Data Analysis

Data analysis followed guidelines set out by Smith et al. (2009), and further guidance on reflexivity from Harper and Thompson (2012). Raw data from audio recordings was transcribed by the researcher. Analysis incorporated five stages, following Smith et al. (2009), shown in Table 1 (see Appendix T for further details).

Credibility Checks

Credibility checks occurred throughout the research process. Checks were performed with a Clinical Psychologist supervisor with expertise in IPA to ensure the supervisor could follow theme development from an idiographic to collective level, and they provided comments as recommended by Smith et al. (2009). Further credibility checks were carried out during stage 5 of the analysis with another Clinical Psychologist with experience of using IPA in the field of intellectual disabilities. Peer supervision was used to facilitate bracketing, to carry out an independent audit of subsections of individual interviews, and when considering themes across interviews. Two supervision sessions with an expert in the field were also used to improve the quality of analysis.

Table 1.

Stages of analysis based on Smith et al. (2009)

Stage	Overview
1	Listening to interviews and reading and re-reading transcripts. Unstructured notes were made regarding powerful recollections of interviews and initial observations about the transcripts.
2	Initial noting of each interview considering descriptive, linguistic, and conceptual comments (Steps 1 and 2 repeated in an iterative process).
3	Exploratory notes were combined into initial emergent themes, considering both the local level and overarching narrative for this transcript.
4	Connections were made between emergent themes for each interview using ideas such as abstraction, subsumption, polarization, numeration, and function.
5	Patterns were looked for across cases by using a master table of themes, showing how themes are nested within super-ordinate themes and illustrating the theme for each participant.

Reflexivity

The philosophical underpinning of IPA is phenomenology acknowledging that it is impossible to completely eradicate the influences of personal and professional experiences and knowledge, as well as hypotheses regarding the data (Smith et al., 2009). Reflexivity in qualitative research is being increasingly recognised, particularly the use of a reflective diary and supervision, and is key to conducting rigorous and valid IPA research (Shaw, 2010; Smith et al., 2009; Gough, 2017). The researcher completed a 'bracketing interview' prior to data collection, had regular supervision with an experienced IPA researcher, and used a reflective journal throughout the research, and

following each interview, to keep a record of personal and professional influences and assumptions (see Appendix U). Peer reflection groups were also arranged with other researchers, providing a safe space to reflect on personal and professional influences, explore where they may have come from and how they may impact on the research process. This included writing the interview schedule, asking questions during interviews, bracketing and interpretation and coding of data. The researcher has siblings with intellectual disabilities alongside many years of personal and professional experiences with people with disabilities. One of the key beliefs of the researcher was that adults with intellectual disabilities and their families do not receive appropriate emotional and practical support from statutory services, particularly from adult social care.

Results

Situating the sample

Participants were ten parents, seven mothers and three fathers, aged 40-65 years (mean: 54.1), of a child aged 18-23 years (mean: 19.8) with an intellectual disability. All children scored below the cut-off on the LDSQ except Simon and Matt, who were the only children to have jobs. All parents considered their child to have an intellectual disability; all children were reported to have attended a special educational needs school and had contact with learning disability services. However, without seeing a confirmation of diagnosis or completing a full intellectual disability assessment, it is unclear whether those children who scored above the cut-off on the LDSQ had an intellectual disability or not. Parent and child characteristics are shown in Table 2 (see Appendix V for additional demographic information).

Overview of Themes

Three superordinate themes were generated from the data, each with two or three subordinate themes and all with a high endorsement rate across the sample. These are presented in Diagram 1 and Table 3 and discussed below with illustrative quotes.

Diagram 1.

Visual representation of superordinate and subordinate themes

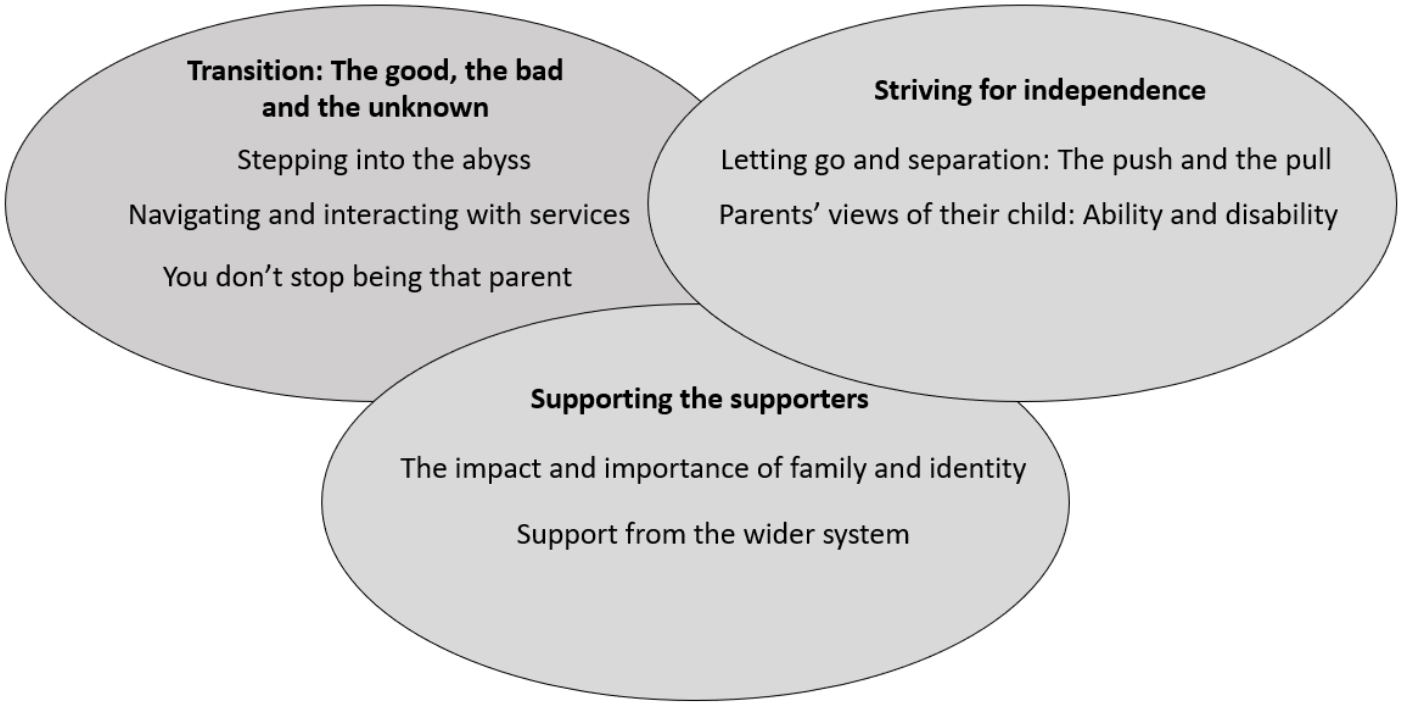

Table 2.

Parent and child characteristics

Parent Pseudonym	**Gender**	**Age**	**Ethnicity**	**Child Pseudonym**	**Gender**	**Age**	**Ethnicity**	**Additional Diagnoses**	**LDSQ Score**
Gill	F	61	White British	Bethany	F	20	White British		0
Sharon	F	40	White British	Sophie	F	20	White British	Down Syndrome	0.29
Debbie	F	60	White British	Jess	F	18	White British	Down Syndrome	0.43
Barry	M	65	White British	Simon	M	23	White British	ASD	0.57
Linda	F	52	White British	Max	M	18	White British	ASD	0.43
Ron	M	65	White British	Jimmy	M	21	White British	Down Syndrome	0.29
Graham	M	54	White British	Matt	M	22	White British	ASD	0.57
Tracey	F	49	White British	Connor	M	18	White British	ASD	0.14
Donna	F	52	White British	Liam	M	18	White British	ASD and ADHD	0.29
Tanya	F	43	White Mediterranean	Gaby	F	20	White Mediterranean	Williams Syndrome	0

Key: F: Female; M: Male; ASD: Autism Spectrum Disorder; ADHD: Attention Deficit Hyperactivity Disorder; LDSQ: Learning Disability Screening Questionnaire

Table 3.

Superordinate and subordinate themes including a breakdown of participants who endorsed each theme

Superordinate and subordinate themes	Total	Gill	Sharon	Debbie	Barry	Linda	Ron	Graham	Tracey	Donna	Tanya
1. Transition: The Good, the Bad and the Unknown	10	*	*	*	*	*	*	*	*	*	*
1a. Stepping into the abyss	10	*	*	*	*	*	*	*	*	*	*
1b. Navigating and interacting with services	10	*	*	*	*	*	*	*	*	*	*
1c. "You don't stop being that parent"	10	*	*	*	*	*	*	*	*	*	*
2. Striving for Independence	10	*	*	*	*	*	*	*	*	*	*
2a. How parents view their child: Ability and disability	10	*	*	*	*	*	*	*	*	*	*
2b. Letting go and separation: The push and the pull	10	*	*	*	*	*	*	*	*	*	*
3. Supporting the Supporters	10	*	*	*	*	*	*	*	*	*	*
3a. The impact and importance of family and identity	10	*	*	*	*	*	*	*	*	*	*
3b. Support from the wider system	9	*	*	*	*	*	*	*	*		*

1. Transition: The Good, the Bad and the Unknown

This superordinate theme relates to the range of emotional experiences parents had regarding the process of their child's transition, including their experiences of statutory services and reflections on the parent role during this time.

1a. Stepping into the abyss. This subordinate theme refers to the experiences of sudden change, uncertainty and worry which many parents alluded to during their child's transition. Parents described moving from feeling that things were containing and predictable in children's services to the unknown feeling of adult services:

> *"it seems very clearly laid out what the whole landscape looks like for children. But as you move into the adult arena it becomes really foggy, very disjointed… you have to find out a lot of it by yourself"* (Linda, 81-84).

Similarly, Gill stated *"when you reach eighteen things generally fall off the cliff and there's really nothing there"* (519-520) whilst Debbie explained *"I'm still not sure what we were transitioning from and to"* (66) and "*it's all a bit vague and waffley"* (142). These comments suggest that parents experience transition as unclear and confusing, with inadequate provision at times, which increase parent levels of stress and anxiety.

Graham described moving from a position of being fully knowledgeable about his child, to his son now making independent arrangements and decisions and not always telling his parents everything, for example arranging his driving test:

> *"you don't necessarily feel there's full disclosure of information of what's going on"* (237-238).

However, Graham reflected that his son's increased independence also reduced the practical and emotional demands on him as a parent, suggesting that as some children

with intellectual disabilities get older some parents can resume a similar role to parents of a child without an intellectual disability:

> "*it has been good in the sense that you can, um, you don't have to be as hands on, you're not fighting fires all the time"* (103-105).

Parents also experienced worry and uncertainty regarding their children exploring adult issues such as sexuality. Tanya spoke of her surprise when her daughter Gaby started exploring her sexuality, something Tanya felt unprepared for, and which led her to question her own judgements and values:

> *"it happened all of a sudden I have to deal with now new, new things… for example I was not prepared for any talk about sex, which I guess I'm learning that I'm more old-fashioned than I thought" (70-73).*

Tracey was also surprised with the sudden change in her son, Connor, wanting a sexual relationship:

> *"I mean that's like a bolt out of the blue that was, and then he turned into an adult and it's like right I can go and have sex now. Go and get me some condoms will you mum [laughs]" (635-638).*

Tracey described discovering this as *"quite difficult…there he was like full on snog on the dance floor, and I went oh blimey, gosh, I'd no idea he was like that, you know, that this was going on"* (652-656). It could be suggested that, at some level, both Tanya and Tracey felt their children would remain child-like. Connor and Gaby's wish for romantic relationships and exploring their sexuality may have challenged the 'eternal child' narratives their parents have. This is new and unexpected territory for these parents who

appear conflicted between supporting their children's wishes and human rights whilst also keeping them safe.

1b. Navigating and interacting with services. All parents referred to experiences of navigating and interacting with services during their child's transition. Many parents described negative experiences of adult services, with a lack of scaffolding and support, in comparison to children's services:

> *"All of these services, as soon as they reach adulthood, do just stop... Even though the need, some of the needs are still there."* (Sharon, 570-575).

> *"There was a lot of support obviously in terms of when he was at school… But once he went to college, um, most of that kind of fell away."* (Barry, 293-297).

These comments suggest adult services are not there for people with intellectual disabilities and their families following transition and many parents are left feeling stranded and isolated.

Additionally, parents often referred to a sense of fighting and battling against services, a lack of trust in them, and a belief that professionals were not competent. Tanya said, "*I don't think they make it that friendly in many ways… and I don't think there's really open mind about when it comes to suggesting things"* (151-156). Debbie stated, *"they're not obviously going to tell you what the criteria are that she doesn't meet"* (141-142). Ron mentioned that dealing with professionals was like a *"minefield if you don't know what you're doing"* (630-631), *"you're asked the same question in four or five different ways to trip you up"* (629-630), and that when parents do fight to appeal decisions they are "*turned over"*(633) which *"just shows you that they're not even looking at them properly in the first place"* (634-635). Barry appeared dismayed at the

seemingly unnecessary bureaucracy associated with his son accessing free health care now he is an adult:

> *"you have to renew that every year which is ridiculous. The lad doesn't stop suddenly having autism from one year to the next"* (353-354).

Similarly, Donna appeared frustrated with the delay in adult health services offering support to her son:

> *"once you go over to the adult ADHD, why don't you just get an invite to go in and review the medication then? ...so we're just waiting now to try and get this medication for his ADHD because he is, he is really hyper"* (528-531).

Gill described the impact of not feeling listened to by services regarding her daughter moving out of the family home:

> *"well you're kind of at your wits ends, you know you think how much more do I have to do to get across what we need to and to get Bethany where we know is the best place for her"* (Gill, 211-212).

Positive experiences of services were also highlighted:

> *"social services have been very supportive to us"* (Tracey, 534)

> *"some of the services try not to treat them different, and they do go visits to the pub and stuff like that"* (Sharon, 427-428).

Some parents described the initial difficulties in accessing support, although once professionals became involved this led to positive outcomes:

> *"we did find adult social care eventually… got in touch with the transition social worker. He was fabulous, he was really helpful… So we got the budget, yey, no problem at all"* (Linda, 132-137).

However, several parents referred to positive experiences being brief and ultimately ending with disappointment:

> *"there was a transition social worker…She understood but she left… because she couldn't do the job anymore ... We actually felt that she was supporting us."* (Gill, 429-432).

Gill's use of the word *"actually"* implies previous experiences of services have not been supportive, which was echoed by Graham:

> *"there was this guy who was going to come and sort it all out for us… he was full of excitement, and then we never heard any more from him"* (318-321).

Debbie also referred to support being short-lived when arranging work experience for her daughter:

> *"I was lucky that I happened to go when there was a helpful person there who had a bit of free time and she's not there a few months later"* (181-183).

The word *"lucky"* suggests Debbie is not accustomed to receiving support from services when trying to get her daughter's needs met. This reflects the consensus from parents that navigating and interacting with services is often challenging and that this contributes to a difficult experience of their child's transition.

1c. "You don't stop being that parent". All parents endorsed this subordinate theme, which refers to how they made sense of their role as parents during their child's

transition. Despite their child having transitioned, parents made reference to the significance of their role and level of parenting, and that whilst the tasks of parenting may have changed, the amount or intensity of input remained the same:

> *"you don't stop being that parent…. but [when you have a child without additional needs] the, the caring aspect of it you, you back off a little bit don't you, and you, you give the care and the attention really when that child is asking for it or is struggling, whereas with Liam that, that hasn't stopped, that's continued"* (Donna, 207-211).

Donna experienced multiple demands including working full-time, caring for Liam, supporting her older son who was moving out, and caring for her dying father and his disabled wife. Ultimately this led to her *"stepping down at work [laughs] not being a manager anymore"* (318). Her use of laughter indicated both a sign of frustration and disbelief at her situation. Donna described how difficult it feels as a mother to need to give her adult son regular prompting, guidance and encouragement:

> *"there's other days where I really struggle with the fact that I am having to give those instructions and they're not being received how I'm saying it"* (139-140).

Parents referred to protecting their child from harm, for example overhearing adult conversations, *"I spoke to her in the garden because I didn't want Connor to hear"* (Tracey, 462-463). This may relate to a sense of ongoing responsibility:

> "*for social engagements you have to facilitate things all the tim*e" (Debbie, 389).

> *"in terms of interacting with any, any organisation, any people, it's really my wife or I that, or the girls even have to, have to do it because he just can't articulate what, what needs to be said or done"* (Barry, 378-381).

> "*I don't want a support worker to be going with my son to his hospital appointment. I think that's my job, that's what I should be doing"* (Linda, 416-418).

The ongoing role was spoken about with both a sense of commitment and resignation:

> *"he'll sit on the bed and he'll talk about stuff and I'm like well I have to because I'm his mum [laughs] and I feel really rotten if I say oh not now I want to go to sleep"* (Tracey, 180-182).

Parents also referred to their role as fighters and advocates and the impact of this:

> *"the hours that we've spent researching, preparing, writing, to fight for Bethany… they don't know the cost of that"* (Gill, 487-489).

Similarly, Debbie reported "*I don't like the fact you have to sort of fight for everything really*" (96-97), Tanya remarked *"I have a battle to fight and that shouldn't be the case. I mean I should get support not fight"* (388-390), and Ron explained *"you're fighting for the, the individual with the disability. You're fighting on their behalf and it's as simple and straight forward as that"* (201-202). When asked how he felt about his role, Ron responded *"[Sigh] I've, sad that you have to fight for everything"* (590-591). Ron's sigh appeared to reflect both his sadness and tiredness with having to continually fight on behalf of his son to get his needs met. This appears to reflect that many of the parents struggled with their continuing role of supporting, fighting and advocating for their child.

2. Striving for Independence

The second superordinate theme encapsulates parents' views of their child's ability and independence and the process of separation and moving on.

2a. Parents' views of their child: Ability and disability. The way parents viewed their child, in terms of their strengths, abilities, needs and disabilities, was often mentioned in relation to transition.

Parents discussed their positive views of their child. Tracey described how *"it has been easier because I think he feels a bit more in control with his life…he'll talk to me more now about stuff…he's more communicative about what he wants and how he would like things"* (234-236) and that her son *"has grown up, um, to become quite, um, kind boy, um thoughtful, um, quite funny sometimes"* (19-20). Likewise, Donna commented how her son *"has got a very caring side to him…a concerned side"* (295-296) and Graham mentioned that as his son *"got older he has become more, almost reflective, in terms of his ability to understand or to, to be able at least to discuss and understand and rationalise the way in which, um, you know, things are happening and what's causing problems and what's not causing problems, and I suppose that has meant that he's been more stable"* (74-76).

Parents also spoke of their child's vulnerability and child-like characteristics in adulthood. Tanya reflected that her daughter, Gaby, has gained confidence:

> *"she's developing more of a personality I guess here. She used to be more, um, how do you say it, docile?... she's fighting back more"* (94-97).

However, Tanya appeared unsure about Gaby's new-found confidence. Gaby is keen to express herself more and break away from her family, which could be viewed as a positive development. However, this increases Tanya's worry and uncertainty, and Gaby may have been perceived as less vulnerable when she was less assertive. Understandably parents feel conflicted as to whether they view their child as an adult or a child *"because there's some very immature emotions but there's also some very mature emotions"*

(Donna, 549-551) and often there is a desire to treat their child *"as a normal person with our family"* (Ron, 69).

Despite transition, parents often identified their child within the context of their disability or diagnosis, perhaps reflecting the degree of support their child requires:

> *"Bethany is profoundly disabled, cannot do anything for herself, is essentially a baby*" (Gill, 9-10).

Similarly, when referring to their daughters, Sharon said *"knowing where she is cognitively… you wouldn't necessarily let a six-year-old run around without knowing exactly where they are."* (475-479) and Debbie stated, *"in terms of Down's Syndrome she's doing well and she's got a lot of interests and activities and, yeah, is happy and thriving."* (32-34). Barry highlighted that one of his son's strengths may also be a vulnerability:

> *"he's not a typical autistic, or he's not what people commonly think of as autistic. He's not the one who sits in the corner and rocks. He's very outgoing, he's very friendly. One might say he's too friendly"* (19-21).

Parents identifying their adult child as vulnerable was apparent in most interviews, especially regarding young adults with milder intellectual disabilities, who often strived for greater independence and required less support. Graham considered his son's vulnerability in terms of his financial capacity when purchasing a television package, stating *"we really felt he'd been ripped off so, um, I wondered whether that was because he was vulnerable or not"* (713-714). Parents' perceptions of their child's abilities and needs often seemed to influence parent behaviour in terms of their willingness to separate from their child and facilitate increased independence.

2b. Letting go and separation: The push and the pull. Associated with the identities parents ascribed their child was parents' sense of letting go, their child leaving home, their child's level of independence, and degrees of importance parents considered these.

Many parents spoke of their experiences of encouraging their child's independence. Linda recognised that as her son *"is getting older I feel for his independence he needs to have more of a, um, he needs to pull away more, particularly from me"* (121-123). Similarly, Debbie stated "*I can leave her for a couple of hours in the house. She doesn't go out anywhere independently on her own"* (233-234) and *"what I always wanted was some sort of, um, one to one support that would take her out and so she wasn't so reliant on me"* (203-204). Often parents wanted to support their child to increase their level of independence. In some cases, parents needed to instigate this, which caused some anxiety. When referring to her daughter going to a weekly social night at the pub, Sharon stated *"I still get a bit nervous, but that's more me letting go then"* (253). Donna highlighted how her son's increased level of independence, in terms of making choices, is not always in line with what the family want:

> *"when they're smaller you have, I think, more control, more involvement, um, and they are quite open to your, um, suggestions influencing, um, whereas Liam now is starting to get an opinion, other people are involved in his life… they're encouraged to make their own choices, those choices are not always the right choices for us maybe as a family, um, so I'm finding it harder caring for an adult child as opposed to a small child"* (49-55).

Parents appeared to be ambivalent about allowing and encouraging independence once their child reaches adulthood. Whilst Donna finds Liam's strive for independence and her

relinquishing control in some areas difficult, she also struggled with Liam's continuing dependence at other times, for example when accessing a shop independently:

> *"I have to talk him through well, you know, we need a loaf of bread, so you choose brown or white. Um, that can cause him quite high anxiety. Facetime is brilliant because he will facetime me and show me the bread etc…He does need, um, reassurance or even help, as in what to purchase"* (88-93).

Some parents described their apprehension about their child moving out and starting a family. Parents reported "*we're not in any great, um, um, hurry to move him out at this moment in time I don't think he's ready for it"* (Ron, 401-403) and *"what kid leaves home at eighteen and does that? So certainly can't do it for special needs"* (Tracey, 626-627) and *"this girl was going on about oh, you know, we're going to get married and have babies, and we'll have three children. No, no, no, this is really not on. And that was quite troubling"* (Barry, 593-595). These comments perhaps highlight parents' apprehension of encouraging independence regarding their child moving out, something that could be linked with parents viewing their children as vulnerable alongside their negative experiences of services. The strive to move out may be instigated by the child themselves, particularly if they observe siblings moving out. It may also be instigated by services in some cases, particularly with the increase in supported living providers over recent years. Overall, many parents expressed a desire for their child to increase independence, however parents appeared apprehensive about them doing so.

3. Supporting the Supporters

This superordinate theme relates to how parents feel they are supported in their role, which includes the influence of the family context and family identity, and accessing support from wider systems.

3a. The impact and importance of family and identity. All parents referred to the impact and importance of their family context and family identity. For some, part of this identity concerned their role as parents and love for their child. This reflected a whole-hearted acceptance of their child and loyalty to them despite challenges they encounter:

> *"wouldn't change her for the world"* (Sharon, 287).

> *"I would die for Max without a moment's hesitation. He is the absolute focus of my world and I love him to bits and I wouldn't swap him for anything"* (Linda, 622-624).

Many parents emphasised aspects of their family identity that were important when considering their child's transition. Gill described the challenges of her daughter, Bethany, leaving the family home and Bethany's carers insisting on offering her meat:

> *"I'm pretty sure if Bethany could talk that she would probably say that I want to be a vegetarian because that's how we are at home"* (361-363).

Gill attended a best interest meeting and used the powers of her deputyship to insist Bethany remain a vegetarian. This suggests some parents have to go to extreme lengths to protect their child and family identity.

Donna referred to the importance of work ethic in her family and expectations that her son will follow suit:

> *"dad is full time, um, he works as a bricklayer, um, leaves the house about, um, seven o'clock… his brother also works full time. So our work ethic in this house is quite good. So hopefully Liam will learn from that"* (21-24).

Graham implied his family are active and outgoing and his son not always wanting to join family outings can challenge that sense of family identity:

> *"when he's slowing us up or when people want to get on and do something and he won't get up or he'll say no, no I don't want to do that"* (397-399).

Additionally, parents referred to their family context and the support available within the family system. Tanya described the importance of integrating with Gaby's step-father's family:

> *"Gaby with my husband's family, she's, they've been great. Um, so basically for Gaby it's like it was a grandma, my mother in-law, and in that sense everything's fine"* (255-257).

Equally, Tanya emphasised the importance of Gaby remaining connected with her biological father's family:

> *"he has another family after. Gaby has younger brother in [another country] but, um, so in that sense she knows, she always knows about everything that's going on. It's not like she doesn't have another side of her family or anything"* (36-39).

When describing her family, Debbie appeared disappointed that her children are not closer and perhaps do not offer as much support to her and Jess as she would like:

> *"they're not that close really. They just get on with each other if they see each other but they wouldn't make an effort to go and see each other… they're all fine with Jess but they wouldn't, you know, they're not, it's not bad, there's no arguments or anything like that"* (380-383).

Graham also referred to the importance of family cohesiveness and a sense of him feeling responsible for ensuring this:

> *"it is quite a stress to actually try and keep a family running and to keep everything happening so that it works for everybody, so you don't limit everyone… having a child with those sorts of issues as the oldest child does have a knock-on effect to all the other siblings because it means you can't discipline in a normal way"* (801-806).

Comparatively, Sharon also hinted at the importance of her family context despite her daughter being an only child. When asked about things that have not changed regarding Sophie's independence, Sharon stated *"I suppose not having any other children it's kind of almost the norm if you like"* (277). Family context and identity, including the parent-child relationship, appeared significant for many parents, particularly during transition.

3b. Support from the wider system. Nine parents referred to experiences of support from the wider system. Many parents discussed the importance of connecting with other parents and families in similar situations. Sharon explained *"you kind of meet them parents and from other clubs and youth clubs, you, you meet other people and they have different stories and different outlooks and have used different services and things, so, so it's kind of, you get lots of information that way"* (80-82) and Tracey commented *"the disabled sports club, swimming club's been, um, a great, um, network for both of us really, and, um, the church com, you know, youth club they've been a good thing as well"* (564-566). Ron spoke of how his lack of trust for respite care stemmed from his connections with other parents:

> *"I suppose talking to people, other parents. Um, and to some, some, some of the, um, the, um, mis-haps that have beset other people"* (382-383).

Ron's comment implies that connecting with other parents is important and has a direct influence on decisions parents make regarding their child's future. Linda commented on the difficulties which occur when parents feel unsupported:

> *"I don't really talk to anybody about that because, um, it's very difficult to find someone who's in exactly the same position as me"* (601-602).

This lack of support results in Linda paying for private therapy to meet her needs:

> *"Most of the time it's ok. Um, there are times when you think (sighs) and I do and that's mainly in my counselling session where I, when all the tears will come and it's just really hard to see everybody else around you and their kids doing things and your child no, so… that's my main support, which obviously I pay for but, um, that's definitely kept me sane"* (685-689).

Similarly, Debbie accesses a talking therapy outside of her existing system, linked to her long-term condition:

> *"I go to a [health condition] therapy centre and I've had counselling through them which has actually been beneficial. I think the counselling was mostly supposed to be about how you deal with [health condition] but I don't want to talk about that I talk about all these other things"* (460-463).

Tanya described how psychological support for children with disabilities and their parents seemed more readily available in her home country compared to England, providing families with much appreciated support:

> *"the system was totally different. So basically over there you have a support because you go once a week to the psychologist, and you just open everything up, and it helps, I think it helps, but I got used to that system"* (471-473).

It appears many parents felt a lack of support for themselves from statutory intellectual disability services during their child's transition. Instead parents often relied on informal support available from the wider systems, such as parent support networks.

Summary of Results

In summary, many parents experienced difficulties and uncertainty during their child's transition, related to their role, their child's independence, navigating services for their child, and accessing support for themselves.

Discussion

The current study aimed to explore the experiences of parents who have a child with an intellectual disability transitioning to adulthood. It resulted in a rich data set from which three superordinate themes arose: Transition: The good, the bad and the unknown; striving for independence; and supporting the supporters. These themes suggested that parents experience a number of difficulties regarding their child's transition. The transition period was often a time of significant stress and uncertainty for parents, many of whom struggled with their child's level of dependence or independence. Services offering support for parents were often lacking and therefore parents had to seek this elsewhere. Superordinate themes are discussed below, and clinical and theoretical implications considered. Limitations of the study and future research directions are also addressed.

Transition: The Good, the Bad and the Unknown

This was a key overarching theme which indicates that parents experienced distress regarding their child's transition, particularly in terms of worry and uncertainty. Parent stress appeared to be related to the overall nature and process of transition, both in terms of the transition to another developmental stage and transition from child to adult services. These findings are in line with existing literature regarding the stress and burden of caring for a child with an intellectual disability (Hassall et al., 2005; Todd et al., 1993) and the impact of transition on daily life and wellbeing (Leonard et al., 2016). Additionally, stress appeared related to the difficulties parents experienced navigating adult services and coping with multiple roles, including the ongoing caring role for their child. This supports the notion that parent stress is related to insufficient and unreliable support services (Griffith et al., 2011) and difficulties navigating services and programs during transition (Leonard et al., 2016). The findings related to parent worry and uncertainty during their child's transition echoes findings by Leonard et al. (2016) regarding 'the second shock', a time of increased parent concern regarding the long-term care of their adult child when they can no longer be the main carer.

These findings have a number of implications. Firstly, to support parents with the stress and uncertainty related to their child's transition, there is a need for statutory services to be more collaborative in their working and provide more information and guidance for parents regarding the transition process and the local services and groups they can access. Collaborative working refers to children and adult services working together across health care, social care and education. However, these ideas are likely to stem from the researcher's pre-existing knowledge and biases regarding local services. Research highlights the importance of involving young people with intellectual disabilities and their parents for a successful transition experience (Kohler & Field, 2003;

Kraemer et al., 2003) and that a lack of involvement results in increased stress and uncertainty (Beresford, 2004). A person-centred plan for every individual could provide parents with information about the services and professionals involved before and after their child reaches eighteen, so everyone should know what to expect and who to contact.

Secondly, and in relation to the aforementioned, there is a need for greater consistency from statutory services and the professionals involved in an individual's care. Many parents in the interviews spoke of professionals being involved for short periods of time in their child's care, and therefore a sense that services do not get to know young people and their families sufficiently well enough to provide effective treatment and care. More consistent and effective care for young people is likely to reduce the demands, stress and worry for parents.

Striving for Independence

This theme indicates the importance of how parents view their child's ability and independence, and how parents make sense of the process of separation and moving on. Perceptions of the child's abilities and needs often appeared to influence parents' willingness to separate from their child and facilitate increased independence. Many parents expressed desires for their child to increase their independence but often appeared apprehensive about doing so. These findings may be considered in relation to lifespan theories and models. People with intellectual disabilities may experience psychosocial stages (Erikson, 1968; Newman & Newman, 2003), developmental tasks (Havighurst, 1972), transitional phases (Levinson, Darrow, Klein, & Levinson, 1978) or developmental stages (Carter & McGoldrick, 1989) differently to people without intellectual disabilities. They may take longer to achieve milestones or complete stages in a different order due to cognitive and adaptive impairments. The major milestone during

transition is leaving the parental home which is known as ‘launching’ (Jezek, 1997). Parents may experience increased anxiety and apprehension due to the ‘the second shock’ (Leonard et al., 2016), the realisation that their child requires increased independence and support from others when they can no longer be the main carer.

In terms of implications, firstly the results highlight the importance of parents and significant others, such as other family members, teachers, and social workers, viewing people with intellectual disabilities as individuals with strengths and needs that are beyond diagnoses and labels. In some cases, it may be an important role for professionals to challenge and educate parents and highlight the young person’s potential and aspirations. This appears to link to the notion of positive risk taking and providing support to parents regarding their understandable worry or uncertainty which may unintentionally prevent or restrict young adults from gaining independence skills. A simple example from this study may be Sharon, who was apprehensive about her daughter making a hot drink in fear that she would burn herself. Clinical Psychologists can support in such cases, helping health and social care practitioners in developing formulations regarding parent and child interactions and behaviours, and introducing the concept of graded exposure to gently challenge parents towards more positive risk taking.

Secondly, families may need long-term assistance to prepare for launching. Parents might need reassurance as they withdraw from their caring role. More consideration is needed into how young people with intellectual disabilities may be best supported to develop friendships and reduce social isolation (Isaacson, Cocks & Netto, 2014). This indicates that communities and services hold responsibility for providing a range of accessible educational, employment, social and respite opportunities for young people to create a stable enough system so that parents may begin to gradually withdraw from their caring role.

Lastly, the findings may reflect the notion that society, and therefore parents, view and treat people with intellectual disabilities as 'eternal children'. Young people with intellectual disabilities may be less likely than their mainstream peers to be exposed to adult issues such as drinking alcohol, learning to drive, romantic relationships, sex, marriage, and having children, due to parents' fears that they would come to harm. Young people with intellectual disabilities may miss out on the gradual process of adolescence, where young people often learn about and experiment with some of these ideas. Consequently, some parents in the current study reported their surprise at their child suddenly engaging in adult-like conversations and behaviour. Services, particularly schools and colleges, may need to consider not whether they broach such topics with young adults with intellectual disabilities, but how they can do this in a person-centred manner that includes the young people and their families.

Supporting the Supporters

This theme suggests that parents experienced the presence or lack of support for themselves as significant. This included a sense of family identity and family context as well as perceived support from the wider system, such as parent networks and talking therapies. Parents in the current study spoke of the importance of informal support, particularly family support and parenting networks. Parent well-being and family quality of life is associated with increased help and emotional support from informal sources, such as a spouse, extended family and friends (White & Hastings, 2004; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014). Similar findings have also been reported regarding parent support networks (Hastings & Beck, 2004).

Additionally, research supports psychological interventions for parents and carers. Interventions exist in other client populations, such as cognitive behaviour therapy groups

for carers of people with dementia. Groups were found to improve carers' physical and mental health as well as producing savings for the healthcare system, reflected in reduced contact with accident and emergency, inpatient and outpatient departments, and mental health services (Allen, 2016). Similar group-based interventions were effective for parents of children with intellectual disabilities (Hastings and Beck, 2004).

The first clinical implication therefore is regarding psychological support for parents. In the current study, parents did not appear to be offered or receive emotional support from intellectual disability services. Instead, many parents were left to seek their own support informally, by paying privately or relying on other health services to access counselling. Improving Access to Psychological Therapies services may be suitable for some parents who are clinically anxious or depressed. However, many of these services do not provide specialist support and interventions for parents and carers. These interventions could be offered routinely in health care services to groups of parents who have children with intellectual disabilities, such as those experiencing transition. The aims of such groups would be to bring parents together who are in similar circumstances; focus on recognising and understanding the demands and stressors of the parent role; and teach skills to parents regarding self-care and coping, including the importance of cognitive appraisals of the parent role. Clinical Psychologists are well placed to organise, facilitate and evaluate such interventions.

The second clinical implication is regarding the importance of informal support. This suggests a rationale for increasing levels of informal support by working more broadly and systemically with couples, siblings and the wider family where there is a person with intellectual disability transitioning. Services may also help support parents by initiating and facilitating parent support networks.

Study Limitations

Findings must be interpreted within the context of a homogenous sample which was largely self-selecting. The demographics of the local area, with most parents identifying themselves as White British, may limit the cross-cultural applications of the findings. Most parents had a child with a mild to moderate intellectual disability. Although efforts were made to check level of intellectual disability using the LDSQ (McKenzie & Paxton, 2006), children's diagnoses were not officially verified. It is unclear whether parent experiences of their child's transition differ depending on the level of their child's intellectual disability. Additionally, participants were not excluded if their child had a co-morbid mental or physical health condition. For example, half of the sample had a child with a diagnosis of Autism Spectrum Disorder alongside an intellectual disability, and therefore it is difficult to separate out the experiences of parents who have a child with an intellectual disability from that of other co-morbid conditions which could also impact on participant's lived experiences. However, including a range of parents of children with intellectual disabilities as well as co-morbid conditions undoubtedly increased the ecological validity of this research.

Future Research

The existing literature emphasises the stress, difficulties and burden of being a parent or carer of a child with an intellectual disability. The findings of the current study suggest that transition is a particularly challenging time of heightened worry and uncertainty for parents. Given these findings, a large scale quantitative study may be helpful, in terms of increasing scalability, to further understanding parent stress and coping during transition. This information could provide evidence for NHS commissioners and third sector services to increase support available to parents during

their child's transition (i.e. 16-25 years) and help to increase parent support networks. There is evidence to suggest that supporting parent stress leads to positive outcomes for their child with intellectual disability (White & Hastings, 2004). As it is unclear whether parents' experiences of their child's transition differ depending on the level of their child's intellectual disability, this could also be an area for future research.

Conclusions

In summary, this research provides an important insight into the experiences of parents who have a child with an intellectual disability transitioning to adulthood. Findings suggest that, during transition, parents experience many difficulties and heightened uncertainty related to their role, their child's independence, navigating services for their child, and accessing support for themselves. These findings may link to results from studies in other countries as well as lifespan theories. A range of clinical implications are highlighted including increased collaboration and consistency from statutory services, providing emotional support to parents, and facilitating parent support networks. It is intended that these findings and recommendations, alongside further research, will help to improve the lives of parents who have a child with an intellectual disability and their loved ones.

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Conflicts of interest

No conflicts of interest have been declared.

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Appendix A

Author Guidelines

British Journal of Learning Disabilities Author Guidelines

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- Education and training
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- New technology
- Policy critique and impact

Its readership is wide comprising members from the British Institute of Learning Disabilities, as well as academics, family carers, practitioners, staff in health and social care organisations, as well as a wide range of others with a personal and professional interest in learning disability, and who wish to promote enriched lifestyles, as well as high quality services and support for adults and children with learning disabilities.

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Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. Brain, 126(4), 841–865. doi: 10.1093/brain/awg076
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Reference

British Journal of Learning Disabilities. (2018). Author guidelines. Retrieved from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156/homepage/ForAuthors.html

Appendix B

Framework to Assess Methodological Rigour According to Quality Standards for

Qualitative Research and for Research in IPA Methodology

Topic	Criterion
1. Research Question	*Clarity of research aims/goals; importance of research; relevance of research; novelty of topic area; clarity of topic/research.* Strong: Novel topic area; clearly conceived; clear aims/goals stated Mixed: Repetitive topic area; arguably conceived; some aims/goals stated Weak: Repetitive topic area; poorly conceived; unclear aims/goals
2. Design	*Justification of research design; Interpretation/illumination of actions and/or subjective experiences of research participants.* Strong: Clear rationale to justify a qualitative approach and for selecting IPA as a suitable qualitative method Mixed: Some, perhaps brief, rationale to justify a qualitative approach and for selecting IPA as a suitable qualitative method Weak: Rationale for a qualitative approach and selection of IPA as a suitable method either not included or very unclear
3. Sampling	*How participants were selected; why selected participants were the most appropriate to provide access to knowledge sought by the study; discussions around recruitment; sample size and homogeneity appropriate to IPA; appropriate perspective taken as befits the research question.* Strong: Sample size ideally appropriate to IPA; sample is appropriately homogenous; clear rationale for selected participants; clear inclusion/exclusion criteria Mixed: Sample size within IPA principles; purposive sampling; some thought to homogeneity of sample; inclusion/exclusion criteria included but may not be clear Weak: Inappropriate sample size, or sample size inconsistent with IPA principles; heterogeneous sample; inclusion/exclusion criteria either not included or very unclear
4. Data Collection	*Justification for setting; clear how data was collected; researcher justifying methods chosen; methods made explicit; an explanation if methods were modified including how and why; form of data made clear.* Strong: Clear justification for and explanation of setting, methods chosen, and procedure involved in data collection Mixed: Some, perhaps brief, mention of how data were collected, and the methods chosen Weak: Justification for and explanation of how the data were collected is either completely lacking or very unclear

Topic	Criterion
5. Reflexivity	*Researcher critically examining own role, potential bias and influence (during formulation of research questions and data collection, including sample recruitment and choice of location); researcher responds to events during the study and consideration of implications in any change to the research design; evidence of at least two of the following: reflective log, bracketing interviews and supervision.* Strong: Reflexivity demonstrated, and explained clearly, throughout process, including pre-research, throughout data collection and analysis; evidence of at least two of the following: reflective log, bracketing interviews and supervision Mixed: Reflexivity demonstrated at least one stage of process; evidence of reflective log, bracketing interviews or supervision Weak: No evidence of reflexivity
6. Ethical Issues	*Sufficient details of how research was explained to participants to assess whether ethical standards were maintained; issues raised by the study are discussed; approval sought from ethics committee.* Strong: Comprehensive ethical considerations; approvals appropriately stated Mixed: Either limited ethical considerations with approvals briefly referenced or strong ethical considerations without any reference to approval Weak: Lacking ethical considerations/approval, or approvals considered without referencing
7. Sensitivity to Context	*Verbatim quotes used; rationale for selection of IPA methodology; claims appropriate to the sample analysed; awareness of and reference to existing literature.* Strong: Use of verbatim quotes; clear selection of IPA methodology and rationale; findings grounded in the data; reference to literature Mixed: Verbatim quotes used, but not representative of whole sample; limited comment on methodology selected; findings not always grounded in the data; minimal reference to literature Weak: Verbatim quotes not used, or used but not representative of whole sample, or used without reference to participants themselves; unclear selection of methodology; findings rarely or never grounded in the data; no reference to literature

Topic	Criterion
8. Commitment and Rigour	*Attentiveness to participants during data collection; appropriateness of sample to research question; reasonably homogeneous sample; clear demographic information; themes supported by verbatim quotes drawn evenly from different participants; transparent credibility/validity checks; reference to supervision* Strong: High attentiveness during data collection interview; demographic information provided regarding homogenous group; themes supported by verbatim quotes; quotes drawn evenly from different participants; transparent credibility/validity checks; reference to use of supervision and processes as to how decisions and conclusions were made. Mixed: Variable attentiveness during data collection interview; limited context provided regarding group; themes not always supported by verbatim quotes; quotes variably drawn from participants; mentions credibility/validity of data; mentions use of supervision but unclear process as to how decisions and conclusions were made. Weak: Lack of attentiveness during data collection interviews; no demographic information provided for group; themes not supported by verbatim quotes; quotes, if used, drawn more from certain participants than others; lack of credibility checking; no mention to use of supervision.
9. Transparency and Coherence	*Descriptions of: how participants were selected, how interview schedule was constructed, how the interviews were conducted, and what steps were used in the analysis (e.g. by use of tables to detail each of these features); exploration of ambiguities and contradictions in the data; consistency with IPA principles; examples of analysis provided; clarity and power of researcher's argument.* Strong: Clear description of participant selection; documented construction of interview schedule; exploration of ambiguities and contradictions in data; consistency with IPA principles; examples of analysis provided, presented clearly with the use of visual diagrams and/or tables; argument is clear and powerfully described Mixed: Participant selection mentioned but unclear; some reference to construction of interview schedule; limited exploration of ambiguities; some or mixed consistency with IPA principles; limited examples of analysis provided, if any, with either no use of visual diagrams/tables or they are present but unclear; argument is coherent Weak: Participant selection not mentioned; no reference to construction of interview schedule; no exploration of ambiguities; limited or no consistency with IPA principles; no examples of analysis provided; unclear or missing argument

Topic	Criterion
10. Data Analysis	*In-depth description of the analysis process; explanation of how the data presented were selected from the original sample to demonstrate the analysis process; sufficient data presented to support findings; extent to which contradictory data is taken into account; researcher has critically examined own role, potential bias and influence during analysis and selection of data presentation.* Strong: Data analysis is described well and presented clearly; good use of data to support the researcher's interpretations and findings; clear consideration of possible alternative explanations/analysis; researcher has clearly and sufficiently critiqued own role, biases, and influences Mixed: Data analysis is either not described well or presented unclearly; some use of data to support the researcher's interpretations and findings; no consideration of alternative explanations/analysis; researcher either shows insufficient evidence of clearly critiquing own role, biases, and influences, or does attempt to do this but is generally unclear Weak: Data analysis not described or very unclearly described and presented; no use of data to support the researcher's interpretations and findings; no consideration of alternative explanations/analysis; no evidence of the researcher critiquing own role, biases, and influences
11. Findings	*Findings are explicit; adequate discussion of evidence for and against the researcher's arguments; credibility of findings discussed; findings discussed in relation to the original research questions.* Strong: Findings are explicit; there is a good level of discussion of evidence for and against the researcher's arguments; credibility of findings discussed clearly; findings are clearly discussed in relation to the original research questions Mixed: Some findings are not explicitly or clearly stated; some discussion of evidence for and against the researcher's arguments; credibility of findings either not discussed or not discussed clearly; some evidence of findings discussed in relation to the original research questions Weak: Findings are not clearly stated; no discussion of evidence for and against the researcher's arguments; credibility of findings are not discussed; either no attempt made to discuss findings in relation to the original research questions or any attempt to do this is unclear
12. Impact and Importance	*Discussion of the contribution of the study to existing knowledge or understanding; identification of new areas where research is necessary; discussion of whether/how findings can be transferred to other populations or consideration of other ways the research may be used.* Strong: Clear impact, useful findings and implications outlined Mixed: Impact noted, limited utility of findings and at least one implication outlined Weak: Finding limited; findings do not consider implications for clinical work or future research

Appendix C

Example Use of Framework (Appendix B)

Agbenyega & Tamakloe (2014)

Topic	Criterion
1. Research Question	*Clarity of research aims/goals; importance of research; relevance of research; novelty of topic area; clarity of topic/research.* **Strong: Novel topic area; clearly conceived; clear aims/goals stated** Mixed: Repetitive topic area; arguably conceived; some aims/goals stated Weak: Repetitive topic area; poorly conceived; unclear aims/goals
2. Design	*Justification of research design; Interpretation/illumination of actions and/or subjective experiences of research participants.* Strong: Clear rationale to justify a qualitative approach and for selecting IPA as a suitable qualitative method **Mixed: Some, perhaps brief, rationale to justify a qualitative approach and for selecting IPA as a suitable qualitative method** Weak: Rationale for a qualitative approach and selection of IPA as a suitable method either not included or very unclear *Some mention of research design but no specific comment on why IPA is selected as a suitable qualitative method*
3. Sampling	*How participants were selected; why selected participants were the most appropriate to provide access to knowledge sought by the study; discussions around recruitment; sample size and homogeneity appropriate to IPA; appropriate perspective taken as befits the research question.* Strong: Sample size ideally appropriate to IPA; sample is appropriately homogenous; clear rationale for selected participants; clear inclusion/exclusion criteria **Mixed: Sample size within IPA principles; purposive sampling; some thought to homogeneity of sample; inclusion/exclusion criteria included but may not be clear** Weak: Inappropriate sample size, or sample size inconsistent with IPA principles; heterogeneous sample; inclusion/exclusion criteria either not included or very unclear *Appropriate sample size but no explicit inclusion/exclusion criteria mentioned.*

Topic	Criterion
4. Data Collection	*Justification for setting; clear how data was collected; researcher justifying methods chosen; methods made explicit; an explanation if methods were modified including how and why; form of data made clear.* **Strong: Clear justification for and explanation of setting, methods chosen, and procedure involved in data collection** Mixed: Some, perhaps brief, mention of how data were collected, and the methods chosen Weak: Justification for and explanation of how the data were collected is either completely lacking or very unclear
5. Reflexivity	*Researcher critically examining own role, potential bias and influence (during formulation of research questions and data collection, including sample recruitment and choice of location); researcher responds to events during the study and consideration of implications in any change to the research design; evidence of at least two of the following: reflective log, bracketing interviews and supervision.* Strong: Reflexivity demonstrated, and explained clearly, throughout process, including pre-research, throughout data collection and analysis; evidence of at least two of the following: reflective log, bracketing interviews and supervision Mixed: Reflexivity demonstrated at least one stage of process; evidence of reflective log, bracketing interviews or supervision **Weak: No evidence of reflexivity**
6. Ethical Issues	*Sufficient details of how research was explained to participants to assess whether ethical standards were maintained; issues raised by the study are discussed; approval sought from ethics committee.* Strong: Comprehensive ethical considerations; approvals appropriately stated **Mixed: Either limited ethical considerations with approvals briefly referenced or strong ethical considerations without any reference to approval** Weak: Lacking ethical considerations/approval, or approvals considered without referencing *Good evidence of ethical work/approach but no mention of the study being registered with an ethics committee.*
7. Sensitivity to Context	*Verbatim quotes used; rationale for selection of IPA methodology; claims appropriate to the sample analysed; awareness of and reference to existing literature.* **Strong: Use of verbatim quotes; clear selection of IPA methodology and rationale; findings grounded in the data; reference to literature** Mixed: Verbatim quotes used, but not representative of whole sample; limited comment on methodology selected; findings not always grounded in the data; minimal reference to literature Weak: Verbatim quotes not used, or used but not representative of whole sample, or used without reference to participants themselves; unclear selection of methodology; findings rarely or never grounded in the data; no reference to literature

	Topic	Criterion
8.	Commitment and Rigour	*Attentiveness to participants during data collection; appropriateness of sample to research question; reasonably homogeneous sample; clear demographic information; themes supported by verbatim quotes drawn evenly from different participants; transparent credibility/validity checks; reference to supervision* Strong: High attentiveness during data collection interview; demographic information provided regarding homogenous group; themes supported by verbatim quotes; quotes drawn evenly from different participants; transparent credibility/validity checks; reference to use of supervision and processes as to how decisions and conclusions were made. **Mixed: Variable attentiveness during data collection interview; limited context provided regarding group; themes not always supported by verbatim quotes; quotes variably drawn from participants; mentions credibility/validity of data; mentions use of supervision but unclear process as to how decisions and conclusions were made.** Weak: Lack of attentiveness during data collection interviews; no demographic information provided for group; themes not supported by verbatim quotes; quotes, if used, drawn more from certain participants than others; lack of credibility checking; no mention to use of supervision. *Attentiveness to participants is evident with an appropriate and reasonably homogenous sample used and some demographic information clearly provided. Themes supported by quotes from a range of participants. However, there is a lack of information regarding transparency/creditability with a lack of reference to triangulation and supervision.*
9.	Transparency and Coherence	*Descriptions of: how participants were selected, how interview schedule was constructed, how the interviews were conducted, and what steps were used in the analysis (e.g. by use of tables to detail each of these features); exploration of ambiguities and contradictions in the data; consistency with IPA principles; examples of analysis provided; clarity and power of researcher's argument.* **Strong: Clear description of participant selection; documented construction of interview schedule; exploration of ambiguities and contradictions in data; consistency with IPA principles; examples of analysis provided, presented clearly with the use of visual diagrams and/or tables; argument is clear and powerfully described** Mixed: Participant selection mentioned but unclear; some reference to construction of interview schedule; limited exploration of ambiguities; some or mixed consistency with IPA principles; limited examples of analysis provided, if any, with either no use of visual diagrams/tables or they are present but unclear; argument is coherent Weak: Participant selection not mentioned; no reference to construction of interview schedule; no exploration of ambiguities; limited or no consistency with IPA principles; no examples of analysis provided; unclear or missing argument *Clear information regarding procedures, how participants were selected and the interview schedule and how it was used. More information about how the schedule was produced could have been included as well as visual diagrams and/or tables to present the results clearly. Overall the argument is clear and well described and the study is consistent with IPA principles.*

Topic	Criterion
10. Data Analysis	*In-depth description of the analysis process; explanation of how the data presented were selected from the original sample to demonstrate the analysis process; sufficient data presented to support findings; extent to which contradictory data is taken into account; researcher has critically examined own role, potential bias and influence during analysis and selection of data presentation.* Strong: Data analysis is described well and presented clearly; good use of data to support the researcher's interpretations and findings; clear consideration of possible alternative explanations/analysis; researcher has clearly and sufficiently critiqued own role, biases, and influences **Mixed: Data analysis is either not described well or presented unclearly; some use of data to support the researcher's interpretations and findings; no consideration of alternative explanations/analysis; researcher either shows insufficient evidence of clearly critiquing own role, biases, and influences, or does attempt to do this but is generally unclear** Weak: Data analysis not described or very unclearly described and presented; no use of data to support the researcher's interpretations and findings; no consideration of alternative explanations/analysis; no evidence of the researcher critiquing own role, biases, and influences *Data analysis could have been described in a clearer way (e.g. use of table/diagrams and listing results according to themes). Data is used well to support themes but now evidence of researchers examining their own role etc.*
11. Findings	*Findings are explicit; adequate discussion of evidence for and against the researcher's arguments; credibility of findings discussed; findings discussed in relation to the original research questions.* Strong: Findings are explicit; there is a good level of discussion of evidence for and against the researcher's arguments; credibility of findings discussed clearly; findings are clearly discussed in relation to the original research questions **Mixed: Some findings are not explicitly or clearly stated; some discussion of evidence for and against the researcher's arguments; credibility of findings either not discussed or not discussed clearly; some evidence of findings discussed in relation to the original research questions** Weak: Findings are not clearly stated; no discussion of evidence for and against the researcher's arguments; credibility of findings are not discussed; either no attempt made to discuss findings in relation to the original research questions or any attempt to do this is unclear *Similar to above, findings are stated but could have been clearer. Researchers do link evidence of findings to the original research questions.*

Topic	Criterion
12. Impact and Importance	*Discussion of the contribution of the study to existing knowledge or understanding; identification of new areas where research is necessary; discussion of whether/how findings can be transferred to other populations or consideration of other ways the research may be used.* **Strong: Clear impact, useful findings and implications outlined** Mixed: Impact noted, limited utility of findings and at least one implication outlined Weak: Finding limited; findings do not consider implications for clinical work or future research *Yes this is covered well in the conclusion section*

Appendix D

Yardley's Criteria Demonstrating the Validity of Qualitative Research

Adapted from Yardley (2000, 2008, 2017)

Sensitivity to Context

A qualitative study could demonstrate sensitivity to context by showing awareness of the participants' perspectives and setting, the sociocultural and linguistic context of the research, and how these may influence both what participants say and how this is interpreted by the researcher. This includes:

- Use of verbatim quotes
- Reference to literature
- Purposive sampling
- Selection of methodology in the context of other qualitative methods
- Data collection and analysis

Commitment and Rigour

Commitment and rigor can be demonstrated by in-depth engagement with the topic, including thorough data collection, displaying expertise and skills in the methods employed, and undertaking a detailed, in-depth analysis. This includes:

- Level of attentiveness during data collection interview
- Purposive sampling to create homogenous group
- Themes supported by verbatim quotes
- Quotes drawn evenly from different participants
- Credibility checks
- Research supervision acknowledged

Transparency and Coherence

Transparency means that the reader should be able to see clearly how the interpretation was derived from the data. This includes:

- Construction of interview schedule documented
- Exploration of ambiguities and contradictions in data
- Consistency of research with principles of IPA
- Examples of analysis process given

Impact and Importance

Importance refers to the requirement for all research to generate knowledge that is useful whether in terms of practical utility, generating hypotheses, or even changing how we think about the world. This includes:

- Useful and interesting data – theoretical, clinical and research implications
- Publication bias
- Journal impact

Appendix E

Journal of Applied Research in Intellectual Disability Author Guidelines

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

1. GENERAL

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

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process. Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles. 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 published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above-mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

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

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'.

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their

location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Permissions

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visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

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

Example of reference with 2 to 7 authors

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

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

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.

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Appendix F

Classifying Intellectual Disability

Intellectual disability and similar terms such as learning disability, learning difficulty, and mental retardation have historically been used interchangeably, creating confusion throughout research (Kavale & Forness 2000; Harris & Greenspan, 2016). The term intellectual disability represents an international shared language and has widely replaced the term 'mental retardation' (Salvador-Carulla et al., 2011; BPS, 2015). Intellectual disability indicates developmental difficulties in intellectual (IQ<70) and adaptive functioning, which must have been present before adulthood (World Health Organisation (WHO), 2007; British Psychological Society (BPS) 2015; American Psychiatric Association (APA), 2013). Intellectual functioning refers to aspects of thinking such as problem solving, processing speed, working memory, and abstract thinking. Adaptive behaviour is defined as the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives (American Association on Intellectual and Developmental Disabilities, 2010).

Diagnosis of an intellectual disability is a permanent, powerful and stigmatising identity with many people with intellectual disabilities unaware of this identity (Beart, Hardy, & Buchan, 2005). Intellectual disability is categorised as mild, moderate, severe, or profound. A distinction is made between intellectual disability, impairments falling two standard deviations below the population mean, and severe intellectual disability, impairments falling three standard deviations below the population mean (BPS, 2015). Diagnosis was primarily informed by a cognitive assessment of intelligence. However, recent concerns regarding reliability and validity of lower cognitive assessment scores (Whitaker, 2013) has resulted in a shift giving more emphasis to adaptive behaviour and

social functioning (APA, 2013) with IQ scores interpreted in the context of adaptive functioning assessment (BPS, 2015). As intellectual disability is a socially constructed phenomenon, developed in Western societies to identify people who struggle to cope independently and may need additional support, it is vital intellectual disability assessments are considered within the context of an individual's socio-cultural and family background (BPS, 2015; Whitaker, 2013). The prevalence of intellectual disability cross-culturally is difficult to estimate because different definitions are used, those including deficits in social and occupational functioning as well as those which rely solely on a measure of intelligence quotient (Allison & Strydom, 2009).

People with an intellectual disability are more likely to have secondary disabilities and co-morbid physical and mental health problems than the rest of the population (Emerson & Hatton, 2014; Einfeld, Ellis & Emerson, 2011; Cooper et al., 2015). They have a shorter life expectancy and greater risk of early death; increased risk of, and death caused by, coronary heart and respiratory diseases; poor general health; and proportionally higher rates of psychiatric disorders and challenging behaviours (Emerson & Baines, 2011). Additionally, approximately 20-33% of adults with an intellectual disability also have autism (Emerson & Baines, 2010).

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Appendix G

A Consideration of Lifespan Models and People with Intellectual Disabilities

Lifespan models and theories highlight some of the differences and potential challenges that young people with intellectual disabilities and their families may face. Eric Erikson (1968) proposed a psychoanalytic eight-stage theory of psychosocial development based on the concept of a changing individual operating in society. As the individual develops new demands are placed upon them which provokes an emotional crisis, the successful resolution of which leads to the development of new strength. Failure to successfully complete a stage can result in a reduced ability to complete further stages and therefore an unhealthier personality and sense of self. Erikson puts a great deal of emphasis on the adolescent period, feeling it was a crucial stage for developing a person's identity. Young people with intellectual disabilities may struggle with successfully resolving even some of the earlier stages, such as hope (Stage 1) if care received is harsh, inconsistent, unpredictable or unreliable; children with disabilities are more likely to be victims of violence than children without disabilities (Jones et al., 2012). Intellectual disability may hinder a child in gaining independence and autonomy (Stage 2), interacting and initiating activities with others (Stage 3), demonstrating specific competencies valued by society such as reading, writing and doing sums (Stage 4), establishing a sense of identity in adolescence (Stage 5), and experiencing the opportunities to explore relationships and intimacy (Stage 6). This in turn has an impact on parents who are often relied upon to provide additional support and encouragement with the person's adaptive behaviour (McConkey, 2005) including: communication, community use, functional academics, home living, health and safety, leisure, self-care, self-direction, social life, and work (Harrison & Oakland, 2015).

Newman and Newman (2003) revised Erikson's (1968) theory to include typical pathology at different stages of life. Young adults with intellectual disabilities are more vulnerable from the outset of experiencing mistrust, shame/doubt, guilt, inferiority, role confusion and alienation (Gilmore & Cuskelly, 2014; Al-Yagon & Mikulincer, 2004). This may result in detachment, compulsion, inhibition, inertia, isolation, confusion and exclusivity. It is understandable therefore that parents and carers may strive and stress to support their young person with an intellectual disability to maximise their experiences of success and minimise their experiences of failure across the different stages. Many people with intellectual disabilities can succeed in the psychosocial stages described by Erikson (1968) and Newman and Newman (2003), however there are likely to be some delays, sometimes with different stages being completed in a different order.

Havighurst (1972) proposes that developmental tasks arise from physical maturation, cultural expectation and the individual's aspirations or values. Havighurst's theory describes 'early adulthood' (18-35 years old) as selecting a mate; learning to live with a marriage partner; starting a family; rearing children; managing a home; getting started in an occupation; taking on civic responsibility; and finding a congenial social group. These tasks may be particularly difficult for young people with intellectual disabilities if, unlike the majority of their mainstream peers, they have not completed tasks from earlier in life such as learning to talk; learning bowel and bladder control; developing basic skills in reading, writing and calculating; achieving personal independence and emotional independence of parents and other adults; achieving new and more mature relations with peers of both sexes; achieving a masculine or feminine role; preparing for an economic career; developing an ideology; and desiring and achieving socially responsible behaviour. Once again, this is likely to have a significant

impact on parents of young adult children with intellectual disabilities who often have to provide additional practical and emotional support resulting in tiredness and stress (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006; Todd, Shearn, Beyer, & Felce, 1993). According to Havighurst (1972) parents at the 'middle age' stage in their developmental tasks are assisting teenage children to become responsible and happy adults, achieving adult social and civic responsibility, developing adult leisure time activities, and adjusting to ageing parents. All these tasks are likely to be affected due to parenting an adult child with an intellectual disability. Additionally, this may be harder if parents notice other parents such as family, friends, colleagues or neighbours thriving and succeeding in these developmental tasks.

Levinson, Darrow, Klein, and Levinson (1978) developed Havighurst's (1972) ideas, proposing that a pivotal concept was the person's life structure or the underlying pattern or design of a person's life at a given time. Life structure evolves through a series of alternating stable and transitional phases which give an overall shape of the course of adult development. It is shaped mainly by the individual's social and physical environment, primarily work and family, but also religion, race and status. Each structure-changing period has features in common with all other transitional periods and each has specific tasks reflecting its place in the life cycle. Levinson et al. (1978) describe 'early adult transition (17-22 years old)' as 'leaving adolescence' and 'making preliminary choices for adult life', and 'entering the adult world (22-28 years old)' as 'making initial choices in love, occupation, friendship, values, and lifestyle'. It is likely to be extremely difficult for adults with intellectual disabilities to successfully achieve these transitions at the times Levinson et al. (1978) suggest, not least because of their difficulties with intellectual and adaptive functioning but also historically their needs

have been downplayed and not met by services (Mencap, 2010; Mencap, 2007), and they continue to be misunderstood and stigmatised (Inglis & Swain, 2012). Parents are expected to experience a 'mid-life transition' (40-45 years old) which includes a time of crisis in the meaning, direction, and value of life, and an awareness of death, and 'entering middle adulthood' (45-50 years old) which includes making new choices, forming a new life structure, and committing to new tasks. It is likely parents with children with intellectual disabilities will be delayed in experiencing these transitions due to the delays with 'settling down' (33-40 years old) or that these transitions will conflict with other stages which are still playing out. For example, it may be difficult for parents to contemplate the meaning of their life, create a new life structure and commit to new tasks when their time and responsibility is predominantly dedicated to supporting their child with a disability transition to adulthood and worrying about the longer-term future (Leonard et al., 2016). In line with Havighurst's (1972) and Levinson et al's. (1978) lifespan models, the current study focused on interviewing parents who have a child with an intellectual disability who are aged 18-25 years old and therefore are expected to have completed the transition from 'adolescence'/'pre-adulthood' to 'early adult'.

Carter & McGoldrick (1989) propose a family life cycle framework which divides the life course of a family into developmental stages that define individuals in the family system. This framework identifies the normal developmental stages of the family lifecycle. Of note here is 'Family of Origin Experiences' which includes 'maintaining relationships with parents, siblings, and peers' and 'completing school'. The 'Leaving Home' stage in this framework includes 'differentiation of self from family of origin and developing adult to adult relationships with parents', 'developing intimate peer relationships' and 'beginning a career'. The major milestone in the transition to adulthood

is leaving the parental home which is also known as ‘launching’ (Jezek, 1997). Families need long-term assistance to prepare for launching, parents may need reassurance as they withdraw from their caring role, and more consideration is needed into how young people with intellectual disability may be best supported to develop friendships and reduce social isolation (Isaacson, Cocks & Netto, 2014). Young people with intellectual disabilities may find difficult to achieve the developmental stages suggested by Carter and McGoldrick (1989) due to potential problems with cognitive ability, communication skills, social skills, regulating emotions, and behaviours which challenge (British Psychological Society 2015; American Psychiatric Association 2013; Emerson et al., 2001).

Bronfenbrenner’s (1979) ecological theory offers an alternative view that development is influenced by five environmental systems. The microsystem refers to the institutions and groups that most immediately and directly impact the child's development including family, school, religious institutions, neighbourhood, and peers. The person’s own biology including sex, age and health may be considered part of the microsystem. The mesosystem includes interconnections between the microsystems, interactions between the family and teachers, and the relationship between the child’s peers and the family. The exosystem involves links between a social setting in which the individual does not have an active role and the individual's immediate context, such as their parent’s work. The Macrosystem describes the culture in which individuals live including socioeconomic status and ethnicity. The macrosystem evolves over time, because each successive generation may change the macrosystem, leading to their development in a unique macrosystem. The chronosystem is the patterning of environmental events and transitions over the life course, as well as sociohistorical circumstances. Young adults

with intellectual disabilities and their families are likely to experience different environmental systems to their mainstream peers. For example, they may experience schools, colleges, day services, housing and work specifically for people with intellectual disabilities (Adult Social Care Statistics Team, 2015). Their development will be affected by the values upheld in their cultural and political contexts.

Given the above models highlighting the stages, tasks and challenges presented to individuals and families as a person progresses to adulthood, as well as the lack of research relating to parental experiences of the various stages, it is appropriate to thoroughly consider the nature and impact of this transition.

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Appendix H

Background to Interpretative Phenomenological Analysis (IPA)

and a rationale for choosing the method

IPA is a flexible and inductive approach with a focus on the individual and patterns across participants which allows for discussion of convergence and divergence (Smith et al., 2009). It is concerned with trying to understand lived experience and how participants make sense of their experiences. Therefore, it is centrally concerned with the meanings which experiences hold for the participants. In allowing parents to reflect on the meaning of their experiences, this approach may help parents identify what was helpful and not helpful, what could be done differently and what changes could occur in the transition process for young people with intellectual disabilities and their families.

The goals of the phenomenology approach contrast with other qualitative methodologies such as discourse analysis, where the goal is to understand how people use language to create and enact identities and activities (Parker, 1992); discursive psychology, concerned with how people make use of available cultural resources and how language functions in specific contexts (Smith et al., 2009); grounded theory, where the goal is to develop an explanatory theory of basic social processes (Starks & Brown Trinidad, 2007); and narrative psychology, which may be interested in the content of people's stories about various events, the relationship between stories, or the stories individuals tell about their experiences, and therefore seems to sit somewhere in between IPA and discursive psychology (Smith et al., 2009). The scale of the current project did not allow for the undefined time scales of grounded theory, which requires ongoing data collection until no new further information is found (Glaser & Strauss, 1967). Additionally, the aim of the current study is to better understand parents' experiences of

their child with an intellectual disability transition to adulthood rather than to generate a model of this. Discourse analysis ideally requires naturally occurring data from a range of sources which would be difficult to collect. Discursive psychology focuses on how people talk about their experiences and the interaction over and above the content of what they say. Narrative psychology concerns the story structures people use to describe events rather than the meanings people make from their lived experience. Thematic analysis may fit with the aim of the research and offer an understanding of participants' viewpoint and perspective; however, this perhaps lacks a higher level of interpretation.

IPA was considered a better methodology as it is a flexible and inductive approach with a focus on the individual and patterns across participants which allowed for discussion of convergence and divergence. Furthermore, IPA is an increasingly used approach across a variety of cultures and has been used successfully to explore experiences of parenting a person with an intellectual disability (e.g. Collins & Coughlan, 2016; Heer, Larkin & Rose, 2015; Boström & Broberg, 2014). Aside from studies by Wilkinson, Theodore and Raczka (2015) and Docherty and Reid (2009), which focused specifically on sexual identity and mothers of young adults with Down Syndrome respectively, there are no studies that have used IPA to explore parental experiences of having a child with an intellectual disability transition to adulthood.

In terms of data collection, a one-to-one interview method was selected. Other IPA studies have used a range of data collection methods including focus groups and interviewing couples. The rationale for selecting individual interviews was that they are the preferred method for ensuring a detailed and extensive investigation into individual experience (Smith et al., 2009). Regarding data analysis, IPA examines experiences from the individual's perspective rather than using predefined abstract categories (Smith et al.,

2009). It employs a double hermeneutic approach which recognises that in exploring the participants understanding, the researcher is influenced by their own world view. Therefore, the analysis is the researcher's interpretation of the participants' understanding and experience (Willig, 2001) and researchers need to be able to identify and reflect upon their own experiences and assumptions (Harper & Thompson, 2012). Analysis in IPA has been described as a 'iterative and inductive cycle' (Smith, 2007). Throughout the process of research preparation, data collection, and data analysis, researchers using IPA are encouraged to be open about themselves and the likely consequences of preconceptions, and to reflect on any preconceptions they can access (Smith et al., 2009).

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Appendix I

Participant Information Sheet

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Having a child with an intellectual disability transition to adulthood: A parental perspective.

PARTICIPANT INFORMATION SHEET

Research Ethics Approval (CUREC 1A) Reference Number: R52766/RE001

1. ***Background and aims of the study***

I am a Trainee Clinical Psychologist at the University of Oxford. I have a master's degree in psychology and am now training to become a qualified Clinical Psychologist. For my training I work part time on clinical placements and part time on my studies. As part of my training I have to conduct research. I would like you to take part in my research.

Before you decide to partake it is important you understand what participating in this research will involve. Please take time to read the following information and ask if there is anything that is not clear or if you would like more information.

This research aims to explore parents' experiences of supporting their child who has an intellectual disability transition to adulthood. This study hopes to answer the following question: How do parents, who have a child with an intellectual disability, make sense of their child's transition to adulthood?

This study is funded by Oxford Health NHS Foundation Trust and the University of Oxford.

2. ***Why have I been invited to take part?***

You have been invited to take part in this study because you are a parent of a child, who has an intellectual disability and is 18-25 years old.

The exclusion / inclusion criteria are:

- You must be fluent in English.
- Your child must have an intellectual disability.

- Your child must be aged between 18-25 years at the time of the interview to capture recent experiences of transition to adulthood.
- You may participate if your child with an intellectual disability also has another diagnosis such as Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder, mental health difficulties, or physical health difficulties.
- Biological, adoptive and foster parents who parented the child with an intellectual disability through their transition to adulthood from the age of 13 years may participate in this study. It is not important that the person with an intellectual disability is still living with their parent at the time of the interview, but it is important that the person with an intellectual disability was living with or had regular contact with their parent during the transition process from the age of 13 up until the change of health and social care services at the age of 18.
- Only one parent for each child with an intellectual disability will be eligible to participate. Both parents of the same child will therefore not be able to participate.

3. Do I have to take part?

No. You can ask questions about the study before deciding whether or not to participate. If you do agree to participate, you may withdraw yourself and your data from the study at any time, without giving a reason and without penalty, by advising the researchers of this decision.

4. What will happen in the study?

- If you to decide to participate you will be asked to sign a consent form.
- You will be asked to answer a demographic questionnaire consisting of questions about your age, gender etc and your child's age, gender etc.
- You will then take part in a 1:1 interview with the researcher at a convenient location. This should take approximately one hour.
- The interview questions will be on the topic of parenting a child with an intellectual disability transitioning to adulthood. Questions will be about your personal experiences of parenting during this time.
- The interview will be recorded on a Dictaphone. This will only be accessed by the researcher and the researcher's supervisors. The only exception to this will be in the event a safeguarding risk is identified (See below 'Is what I say confidential')
- You will be paid £20 as appreciation for your time.
- There will not be any follow-up visits.

5. Are there any potential risks in taking part?

There are no known risks to taking part in this research. If you feel uncomfortable at any point during the interview you can stop. The researcher is a Trainee Clinical Psychologist under supervision and has developed skills in managing and supporting people in emotional distress. Although it is not expected that participants will experience high levels of distress during the research interviews, talking about some of the more difficult or challenging aspects of parenting a person with an intellectual disability may be emotional, and this will be acknowledged with empathy and sensitivity by the researcher. Debriefing will be offered following the research interviews, providing information and support that is available such as websites, carers groups and taking therapies.

6. Are there any benefits in taking part?

Very little research has been carried out on parents' experiences of having a child with an intellectual disabilities transition to adulthood. Finding out more information may help other parents/carers and services.

7. Expenses and payments

You will receive £20 for participation.

8. What happens to the data provided?

The research data and personal/sensitive data will be stored using an encrypted Universal Serial Bus (USB). All audio recordings and information gathered during this research study will be stored securely in a locked container at the researcher's home initially and then at the University of Oxford in accordance with Data Protection Act 1998 and will be destroyed after ten years.

Your responses will be anonymised. Pseudonyms will be used and any identifying information will be changed or removed. Information disclosed about other people, for example relatives and friends, will be treated in the same way, with information anonymised if included in the write up. The researcher and the researcher's supervisor will have access to all data. Participants will be asked for their permission to use direct quotes. All research data and records will be stored for a minimum retention period of 3 years after publication or public release of the work of the research.

If you share information during the interview which leads me to be concerned about your safety or the safety of others I will discuss these concerns with my research supervisors. If a safeguarding risk is identified, I am required to follow Oxford Health NHS Foundation Trust Safeguarding Adults Policy and Procedures. This may require me to break confidentiality and discuss issues with the local safeguarding team and other relevant agencies.

9. Will the research be published?

The research may be published in the Journal of Applied Research in Intellectual Disabilities. This 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.

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

If you agree to participate in this study, the research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through the University of Oxford Central University Research Ethics Committee (reference number: R52766/RE001).

11. ***Who do I contact if I have a concern about the study or I wish to complain?***

If you have a concern about any aspect of this study, please speak to the relevant researcher, Jon Codd [01865 226431], or their supervisor, Dr Oliva Hewitt [01865 226431], who will do their best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the relevant chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:

Chair, **Social Sciences & Humanities Inter-Divisional Research Ethics Committee**; Email: ethics@socsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

12. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Jon Codd

Oxford Institute of Clinical Psychology Training

ISIS Education Centre

Warneford Hospital

Oxford

OX3 7JX

Tel: 01865 226431

Email: jonathan.codd@hmc.ox.ac.uk

Appendix J

Demographic Questionnaire

Sex of Participant:

☐	Male
☐	Female
☐	Rather not say

Ethnicity of Participant:

White:

☐	White British
☐	White Irish
☐	Any other White Background (please specify) _____

Black or Black British:

☐	African
☐	Caribbean
☐	Other Black background (please specify) _____

Asian or Asian British:

☐	Indian
☐	Pakistani
☐	Bangladeshi
☐	Any other Asian Background (please specify) _____

Chinese or Other Ethnic Group:

☐	Chinese
☐	Any other Ethnic Group (please specify) _____

Mixed Ethnic Background:

	White and Black Caribbean
	White and Black African
	White and Asian
	Gypsy and Traveller
	Any other mixed background (please specify) _____
	Rather not say

Age of Participant:

Religion of Participant:

	Agnostic
	Atheist
	Baha'i
	Chinese (Taoist)
	Hindu
	Buddhist
	Christian
	Humanist
	Japanese (Shinto)
	Jewish
	Muslim
	Pagan
	Rastafarian
	Sikh
	Spiritualist
	Other
	Not recorded
	Rather not say

Sexual Orientation of Participant:

☐	Heterosexual/Straight
☐	Gay/Lesbian
☐	Bisexual
☐	Other
☐	Rather not say

Relationship Status of Participant:

☐	Single
☐	Married/Civil Partner
☐	Divorced/Person whose Civil Partnership has been dissolved
☐	Widowed/Surviving Civil Partner
☐	Separated
☐	Rather not say

Sex of Person with an Intellectual Disability:

☐	Male
☐	Female
☐	Rather not say

Ethnicity of Person with an Intellectual Disability:

White:

☐	White British
☐	White Irish
☐	Any other White Background (please specify) _____

Black or Black British:

☐	African
☐	Caribbean
☐	Other Black background (please specify) _____

Asian or Asian British:

- [ ] Indian
- [ ] Pakistani
- [ ] Bangladeshi
- [ ] Any other Asian Background (please specify) _____

Chinese or Other Ethnic Group:

- [ ] Chinese
- [ ] Any other Ethnic Group (please specify) _____

Mixed Ethnic Background:

- [ ] White and Black Caribbean
- [ ] White and Black African
- [ ] White and Asian
- [ ] Gypsy and Traveller
- [ ] Any other mixed background (please specify) _____
- [ ] Rather not say

Age of Person with an Intellectual Disability:

Religion of Person with an Intellectual Disability:

- [ ] Agnostic
- [ ] Atheist
- [ ] Baha'i
- [ ] Chinese (Taoist)
- [ ] Hindu
- [ ] Buddhist
- [ ] Christian
- [ ] Humanist
- [ ] Japanese (Shinto)

	Jewish
	Muslim
	Pagan
	Rastafarian
	Sikh
	Spiritualist
	Other
	Not recorded
	Rather not say

Sexual Orientation of Person with an Intellectual Disability:

	Heterosexual/Straight
	Gay/Lesbian
	Bisexual
	Other
	Unknown
	Rather not say

Relationship Status of Person with an Intellectual Disability:

	Single
	Married/Civil Partner
	Divorced/Person whose Civil Partnership has been dissolved
	Widowed/Surviving Civil Partner
	Separated
	Unknown
	Rather not say

Intellectual Disability

Items from the Learning Disabilities Screening Questionnaire (LDSQ; McKenzie & Paxton, 2006) are used to help clarify the intellectual disability status of the person the participant will be referring to in the research interview.

Appendix K

Learning Disability Screening Questionnaire (LDSQ; McKenize & Paxton, 2006)

The Learning Disability Screening Questionnaire (LDSQ; McKenzie & Paxton, 2006) was developed to help professionals measure whether adults may have a learning disability or not. The questionnaire can be completed with a person or somebody who knows the person well. It has seven items, each scoring 1 or 0 points, which are then added together to provide a total score which can be converted into a percentage score. The higher the percentage score, the less likely it is that the person has a learning disability. The LDSQ reports high levels of accuracy of identifying people with and without a learning disability, with good content validity, sensitivity and specificity reported.

Appendix L

Details on Interview Schedule Development and Service User and Carer Involvement

Focus Groups

In planning this research and considering useful topics to explore with parents, three small focus groups were held with young adults at a school sixth form for students with special educational needs. Focus groups consisted of 4-6 students with a member of staff present to help facilitate. Advice was sought from the young adults about the topics that might be important and the sorts of questions the researcher could ask when interviewing parents. A short discussion was held regarding the purpose of research and this study. Open questions were asked about their experiences of "growing up" and possible questions and topics for parents to consider. Further information was elicited from students using additional prompts and circular questioning. The young adults discussed their experience of growing up, what went well, what was difficult, and what their parents might think about it. The groups' ideas broadened the researcher's consideration of topics to consider. For example, when asking parents about their child becoming an adult it also feels important to consider their child's hopes and expectations (e.g. to drive a car, get married, go to work, and have children). The interview schedule was written with this feedback and the research question in mind.

Initial Letter to Parents/Carers

30th September 2016

Dear parents/guardians and students,

I am a Trainee Clinical Psychologist working for Oxford Health NHS Foundation Trust. I previously worked as one of the support staff in the [redacted] Sixth Form several years ago. I am writing to you as I am in the process of planning a research project to find out about the experiences of parents and carers who have a child with an intellectual disability. I am particularly interested in parent/carer experiences as their child transitions from childhood to adulthood.

Research on the needs and experiences of people with intellectual disabilities and their families is critically important. Unfortunately, there has generally been a lack of research in this area. As the involvement of service users is important in clinical research, I am seeking the advice and support from young people with intellectual disabilities in planning this project. I would like to ask small groups of young people with intellectual disabilities about what they feel the important topics are around growing up and what questions I should be asking parents/carers of young people with an intellectual disability. I then intend to use this advice and information in developing an interview schedule to be used with parents/carers for the research study.

I have spoken with [redacted] about the possibility of coming to [redacted] Sixth Form for a morning or an afternoon one day before the Christmas break. I intend to speak with small groups of about 4-5 students at a time, to discuss what research is and get advice from them for my project. Students can choose if they want to join in with the small group discussions and they are free to withdraw at any time. Please feel free to email me (jonathan.codd@hmc.ox.ac.uk) or speak with [redacted] if you have any

questions or concerns. Please inform [redacted] if you do not wish for your son/daughter to participate in the small group discussions.

I am very grateful to any students who wish to take part and the support of parents/carers and [redacted] School and Sixth Form.

Yours Sincerely,

Jonathan Codd

Trainee Clinical Psychologist, The Oxford Institute of Clinical Psychology

Introduction to Focus Groups

Go around and ask to introduce names and say an interest.

What is Research?

- Scientific
- Investigating
- Solving problems
- Finding answers to questions
- Finding facts
- Studying the world to find new ideas
- Searching for knowledge
- Start with a question, then design/plan research, collect data/information, look at the data/information to see what we find, tell people about it, and then ask some more questions!

What is my Research About?

- There hasn't been much research about people with learning disabilities and their families.
- When people turn 18, by law, they change from being a child to an adult.
- I want to talk with mums and dads who have a child with a learning disability. I want to know what it is like for mums and dads as their child grows up and changes from a child into an adult.

Why I need your Help

- What sort of questions do you think I should ask mums and dads?
- What has been good about growing up?
- What has changed for you?

- What things do you find easy?
- What things are difficult?
- What things might your parents want to talk about?
- What might they say has been easy or difficult?

Group 1 Ideas and Themes

- How old and how long?
- How does it feel?
- When did you find out?
- Having somebody to talk to/support.
- How did you know?
- Role of friendship
- Getting to understand child with special needs.
- Hospitals, nurses, doctors
- What special needs does your child have?
- What about physical health?
- Perception/sight issues makes things difficult
- Permanence of learning disability makes it hard
- Mainstream school was really hard
- Practical changes growing up
- What does it feel like when child grows up so quick?
- More active/talkative now older
- Making friends and keeping friends
- Anxiety and worry
- Motivation to do things

- Relationship difficulties
- Social media, phones, texting
- Sex and sexualised behaviours

Group 2 Themes and Ideas

- What is the family? How is it?
- Strengths of the child with a learning disability?
- Understanding- need to be reminded and things repeated.
- Learning is good for the brain but difficult
- Illness
- Change in work/homework when older
- What do they learn? Exams? What level disability?
- Independence- experience, work, jobs, driving, shopping, money skills
- How confident/brave are they (e.g. talking to strangers, communication)?
- The future- leaving college, university?
- How was the diagnosis?
- Behavioural difficulties? Other diagnoses (e.g. ADHD/ASD)?
- What job/employment?
- Knowing people well (teachers, family, friends).
- Bullying for having a learning disability and not understanding.
- Change in the work at school- harder, more challenging which is good.
- Does your child like their disabilities or understand?
- Being in love/marriage
- Physical changes like voice breaking, breasts
- What will the future be like? Will they be a mother or father?

- Early life experiences and how it affects adulthood.
- Religion/culture/belief systems.

Group 3 Themes and Ideas

- Christmas and parties
- Medical problems and what to do
- Work
- Drinking and getting drunk
- Driving
- Feeling older
- Working hard, earning money, getting up
- Enjoying work, being helpful
- Brothers/family helping me (e.g. with lists, invitations and being independent).
- Friends- going out, shopping, being nice, falling out.
- Relationships
- Living by myself, scary, fun
- Choices of things to do when grow up
- Periods/physical health problems
- Day trips out (e.g. Chessington)
- Behaviour

Research Seminars

On Tuesday 21st February 2017, a research seminar was held where the research proposal was presented to peers, a course tutor and parents of a young adult with an intellectual disability. The purpose of the seminars was to get feedback on the research proposal at an advanced stage, including from representatives of the participant group

that the research was focused on. Specifically, feedback was sought regarding the proposed interview schedule.

Interviews

The interview was developed through focus group consultations with young adults with intellectual disabilities; parents of a young adult with an intellectual disability; a carer from the university service user and carer subcommittee; colleagues of the researcher working in a community team for people with intellectual disabilities; and two supervising Clinical Psychologists. Feedback on draft interview schedules led to changes in the way questions were asked, additional prompts, as well as topic areas. The final interview schedule incorporated suggestions from the guidance and consultation whilst also adhering to guiding principles of IPA methodology (Smith et al., 2009). A bracketing interview established the researcher's prior assumptions and biases, to attempt to set these aside throughout the research process (Appendix N).

Dissemination

Participants were asked if they wished to be sent a summary of the research findings and explore with them who else they feel may benefit from knowing the research outcomes. The researcher intends to contact local organisations to discuss and present findings with people with intellectual disabilities, parents and services.

References

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

Appendix M

Interview Schedule

There hasn't been much research into the lives of people with intellectual disabilities and their families, compared to other areas in health care. "*[Transition to adulthood] is often very challenging for young people with a learning disability and their families: it combines a change of services and professionals at the very time when they are also negotiating wider changes to their life, for example in their educational circumstances."* (Mencap, 2016).

This research study aims to explore parents' experiences of their child with an intellectual disability transition to adulthood.

1. Can you tell me about your experiences of being a parent as X transitioned to adulthood?

   Prompts:

   - What parts were easy/difficult?
   - Can you tell me a bit about any positive/negative experiences?
   - What changed? How did that feel? What impact did the change(s) have?
   - Personal care/Physical health
   - Finances
   - Work/Study
   - Relationships
   - Hobbies/Interests
   - Developing skills (e.g. use of technology, driving, home skills, social skills)
   - How was the experience of change/no change for you as a parent?

2. What was it like for you being in your family as X transitioned to adulthood?

   Prompts:

   - Who else is in the family system?
   - Did anything change in your family at this time? How was that for you?
   - Was there anything that didn't change in your family at this time? How was that for you?
   - How did the family dynamics seem to you at this time? What was that like for you?

3. Can you tell me a bit about your experience in supporting X as he/she transitioned to adulthood?

   Prompts:

   - What did you do to support X? What things did you do? How has this changed? What was that like for you? (e.g. mental health, physical health, independence)
   - How did you feel about your role at the time? What do you think about it now?
   - What things did you think were important/weren't important? Has that changed at all now?

4. Can you tell me about your experience of the support X received as he/she transitioned to adulthood?

   - Were there other support networks/services? What were they like? What's it like now?
   - What support networks/services weren't there? What was that like? What's it like now?

5. Can you tell me about your experience of the support you received for yourself as X transitioned to adulthood?
    - Were there other support networks/services? What were they like? What's it like now?
    - What support networks/services weren't there? What was that like? What's it like now?
6. I asked you at the beginning to tell me about your experiences being a parent as X transitioned to adulthood? Is there anything that you'd like to add?

    Prompts:
    - Has anything changed?
    - Anything come up that didn't at the beginning?

    List of generic prompts:
    - Can you tell me more?
    - Can you explain what you mean by that?
    - What happened before/after that?
    - What changed?
    - How did that feel for you?
    - What were you thinking at the time?
    - What do you think about that now?
    - How did you react to that?

References:

Mencap. (2016). *Transition into adulthood*. Retrieved from https://www.mencap.org.uk/advice-and-support/children-and-young-people/education-support/transition-adult-services

Appendix N

Bracketing Interview (9th October 2017)

Interviewer 1: Would you mind just telling us the title of your research?

I've got to try and remember it now. Um, so, I can't remember the title off by hand, it's basically I'm going to be interviewing parents who have a child with a learning disability between the age of 18 and 25, um, about their transition to adulthood. So about the parents' experience of their child's transition to adulthood.

Interviewer 2: And have you any previous experience related to this topic?

Not in terms of research but from my sort of personal experiences of being a support worker and having family members with learning disabilities, yes. So like the process of, um, going through special needs education and then like transitioning on to sixth forms or colleges and then following that into adult services, and also the change between child services and adult social care. Um, yeah, although I've never been part of those meeting. We used to have social workers come round all the time for [siblings] so used to get home from school and there'd be another social worker eating our biscuits (laughter).

Interviewer 3: What brought you to this topic? What drew you to this particular question?

I was really keen on, like because I think my sort of passion and background is learning disabilities and I was really keen on, um, doing my research in the learning disabilities field, and it was only when I got chatting with [supervisor] about it that we sort of hit a sort of theme, an area where a lot of families are struggling, which tends to be around transition and, you know, the change in services, and I think personally from a background of speaking to loads of people about how things have changed and not always for the better, so there's that sense there that, um, you know, people haven't been offered enough support or the families have been left a bit in the lurch caring for their

child and, um, there isn't much research in learning disabilities in general compared to what we have in like in physical health and mental health. Um, really when I was looking there's only been like research, like proper good research, done in like the last ten to twenty years, which is nothing really. So really any research in the area of learning disabilities I think is gratefully received at the moment. Which is quite lucky really because it gave me a broad range of topics that I could potentially choose from, there's like so much that needs to be done.

Interviewer 4: So what are your hopes for the outcome of this study?

Well I hope that, I hope that parents' voices, that the study allows parents' voices to be heard, um, both individually through like obviously quoting within the project, but also like collectively, so like the themes that come out of it as well, and therefore it might make, um, services, commissioners, sort of sit up and listen a bit more. I mean I know you're only taking a handful of participants and just getting a few, like a few views, but, um, yeah, I'm thinking if common themes come up and they are shared then that's likely to reflect to some extent the wider population as well. I mean, just to think a bit more about that, I'd like, I'd like this research maybe to trigger, um, more research as well. So like if, you know, if it becomes apparent that transition is a difficult time and it's something that parents and families are struggling with, that other researchers might be keen to like pick up on that and maybe do bigger projects as well, like maybe to find out like specific things like to do with education or to do with family life or to do with sex and relationships, like they can look at different areas in more depth.

Interviewer 1: Is there anything that you anticipate that might surprise you in conducting this research?

I guess I'm going into this research expecting a lot of negativity but that's hopefully what my questions are going to try and open up worries, distress, concerns and that, so I guess I'd be surprised if I was interviewing a parent and they had lots of good things to say. So I'm kind of going there, I don't want to sort of lead to saying just about the negatives but I'm expecting it to be quite, I'm expecting them to be talking about quite an emotional rollercoaster when it comes to transition.

Interviewer 4: And what is that based on, like your expectations of it being negative, their experiences being negative?

I think it's just based on what people have already said to me like in the past. So when people have talked about their child moving on from school to college, it's usually oh and it's, you know, this happened and that happened, and it's been really stressful for them, it's been stressful for us, and I think, um, you know, the issues that have come up with some of my sister's friends around like sex and relationships and alcohol and, you know, wanting to move away and be more independent but they can't quite be independent, I think like that, those issues kind of come up quite a lot. Um, yeah, so I'm expecting to hear about those issues mostly. So, what was the question again!?

Interviewer 4: It was what was that based on, you said it was going to be

Oh yeah, and also, like even from parents that I don't know very well, so this lady that I've booked in to see next week, I've not actually met her before, she was somebody that [supervisor] put me in touch with, and as soon as I mentioned to her about what the project is about, she said oh don't get me started, and she started to just offload and I had to sort of say to her this is really great and this is what we want to talk about in the interview don't tell me everything now.

Interviewer 4: Yeah so you've got a glimpse already.

Interviewer 3: Is there any, so you spoke about having siblings with, um, learning disabilities, and like having previous contact with, like worked quite a lot with people that have learning disabilities, do you think, I guess that might influence what you're expecting to find already because of those negative assumptions about what transitions like, but is there any other ways that you think those prior experiences will influence, um, the interviews, either positively or negatively?

I think yeah on a negative one, like I have thought about this, because obviously it's great that I have a bit of natural empathy and understanding about what people are talking about but at the same stage I don't want that to lead into me being too leading in terms of the things that I've noticed and experienced, I don't necessarily want to end up asking about those things assuming that they've come up for other people and they might not have done. Um, but on a positive front I think because I'm quite aware of the nature of the field and kind of the services that there are and the services that there aren't, I think that will help quite a lot because sometimes I find that if I'm speaking to somebody about a topic that I don't know about a lot of the [audio disrupted] ok if they say something about Mencap or they're saying something about a particular service of if they're talking about [name of borough] say for example, then I sort of have an understanding of the context that they're talking about, so I think that's helpful.

Interviewer 2: You said about that you might be worried about leading participants during the interview, things you're interested in, is that one of the main worries or concerns or is there any other?

Yeah, I think that's the main thing that could end up or becoming fixated on like one particular sort of topic and not allowing the interview to kind of broaden out to allow for other perspectives as well. Um, so like at the moment for my little sister one of the main

things we're having a tough time around is like her being in a relationship and kind of managing that, but then there are lots of young adults with learning disabilities that aren't in relationships, aren't thinking about sex or marriage or getting pregnant or anything like that, and so that's not an issue, so to sort of, I don't know, like just be mindful that, you know, that there aren't necessarily common themes for everybody.

Interviewer 1: Have you had any ideas about how you might achieve that balance in the interview?

I think initially, although I don't want to be sitting there with a piece of paper, I think allowing kind of me to use some of the questions that I've already got, because I've tried to make them as open as possible so they're likely to, um, so just asking things like, rather than saying or assuming that relationships might have been tricky between siblings, just asking more generally what was it like in the family, being in the family, as your child was going through that stage, and just seeing then what the participant brings and then following that up, rather than going in too specific straight away. Um, but I'm going to try and just ask more generally about their experience of transition like from the go and then hope to be honest that a lot of parents will have enough just to talk quite a lot anyway without me having to interrupt. Um, and also it sort of helps because if your with the participants, like I indirectly know already, so I can kind of anticipate some of the things that might come up and some of the things they might talk about anyway. I think that is both helpful and unhelpful, because it's unhelpful you don't want to end up probing those areas if they're not naturally bringing them up, but it's helpful because you kind of know maybe a little bit what to expect and how, you're already thinking about, um, questions that you might ask if that comes up, how to explore it further.

Interviewer 3: Do you think, um, there's any possibility that you might be personally affected by the interviews and in what way?

I haven't really thought about that. It's a good question. Yeah, I guess because it's quite close to home it is quite an emotional subject for me and it's something that I'm quite passionate about and I do feel quite angry about sometimes as well. Um, I guess I don't imagine it making me feel really upset but I can imagine that the most it would do, if somebody's becoming quite irritated, emotional, frustrated when they're talking about their experiences, I know that often that will, like when we're working in therapy, like quite often there is that projection anyway, but I think because I'm already more likely to feel it, it's going to be sitting there already so it's going to be quite easily triggered. Um, I guess I just have to be aware of my body and my emotions during the interviews and try and, yeah, try and not let that influence like my questioning too much and then try and think about that after the interview because I did wonder about that actually, because I've potentially got two participants on one day, and I was thinking if there are two back to back then that might be quite tricky because then you're not getting a gap to actually reflect and, um, think about what the interview brought up for me. So that's quite helpful actually because it might be better to do one first thing in the morning and then one later on in the afternoon so there's quite a bit of processing time in between. Yeah, and ideally, I wouldn't have two on one day, it would be nice to do like one a week and have like a whole week to kind of think it through, but half terms coming up so I want to try and catch parents when they're likely to be available.

Interviewer 2: And what drew you to the type of analysis that you're using?

Um, in all honesty IPA it's the thing to do isn't it, if you're doing qualitative do IPA (laughter). Um, but actually although I put the cart before the horse in terms of doing

IPA, the more I've read and learnt about IPA the more it fits what I want to do anyway, which is purely about finding out about somebody's experiences of something, so that kind of fits. And I do like the whole idea of it allowing you to bring in your own ideas and thoughts and be quite reflective and open about that as well, like it's part of it, it's not asking you to shut off your own experiences and opinions and things, you can allow for that, like when you're writing up.

Interviewer 3: You said that you did know some of the participants indirectly. Um, how have you, yeah, what's been your thoughts and processes about selecting participants?

Yeah so, I've thought quite a bit about it and I think it went to and fro because initially when I was discussing with [supervisor] I think she was keen for me to think about a broad range of people that I'm interviewing. So, for example, my family are quite involved with a disabled sports club, so I wouldn't want to just be recruiting from one like club. Um, but thankfully through like, you know, word of mouth and things, like I've managed to get friends of friends and things like that as well so there's a range of people that I do and don't know, and there's also a range of people from different areas as well so some of them live in like the [town] area and some of them live in the [another town] area, some of them live over in [another county]. Um, and that's quite important I think because you don't just want everybody talking about an experience of like [borough] for example, which, you know, would be quite narrow. Um, I think already knowing a participant I think is more of a positive than a negative because if you're going into an interview and you've already, someone already kind of knows who you are, some of them might be like oh you're [name of mother]'s son, yeah, so there's already like an element of we know the family, um, kind of, there might be a bit of trust there, there might be a bit of rapport if I've had conversations with them before. Um, and in some cases I may have

even supported their child in some cases like doing a boating activity or swimming or something like that. So I think that's kind of nice because if they think oh [researcher]'s going to be nice, you know I feel like I can talk to [researcher] or can be completely honest and open with him, I think that helps the IPA process, because, I'm not saying I won't have to do any work in developing that rapport like during the interview, but if there's already that there at the start then hopefully you can get into the nitty gritty stuff like quite early on and it won't take like half an hour of an interview for somebody to feel like they can be emotional, or open up, or whatever.

Interviewer 1: I'm wondering if you've thought about boundaries after the interview? Will these be people that you continue to see in the community or?

Yeah, um, I think I will just have to reiterate like what's in the consent form around confidentiality and basically saying, you know, I mean the things is as well because my family know some of them on a personal level as well, if I feel like something really significant came up, um, not necessarily around risk but, I suppose it could be risk, but like if something significant came up, like if the family were really struggling with something, that it would be hard for me to see them next time and not check in with how things are follow that up. So I think like if something did come up then at the interview I would say obviously we're going to see each other again possibly after this interview, like is it ok for us to talk about this stuff or would you rather we didn't, and, you know, if we do, like, how will I know that's ok, and just kind of asking those sorts of questions really, so like I don't start opening up a conversation again in the future that isn't wanted or like necessary.

Interviewer 1: Yeah, I guess I was just thinking if something came up like safeguarding or risk or, how that might feel for you holding that and yet potentially having ongoing contact?

Um, well I'm assuming that if something risky or safeguarding came up then I'd have to do what I do with any participant and just follow the protocols that I said I would for in terms of Oxford Health and obviously I think I'd just have to discuss it with [supervisor] and kind of go from there. Um, yeah, it would be really tricky if I had to then report something to the police or social services. Um, in a way that's one really good reason for not interviewing people that you know. But then I guess you weigh up the balance of what are the chances of something like that coming up, and because I know the context and I know quite a few of the families, I may know that there are issues there but I'm not, I'm not aware of or not expecting there to be any significant kind of risky issues, like with some of the parents I know are very good and I wouldn't expect there to be any safeguarding issues, within the families, like there might be some stuff that comes up through college or school and to make sure that those things are being addressed.

Interviewer 4: Have you thought about, I was thinking when you asked that question about what happens if your mum asks you about the different interviews, like have you thought about your boundaries there or what you might say?

Yeah I think I will just say to my parents from the start that I can't talk about, I will just basically say like if you are interested you can always ask them themselves how did you find the interview with [researcher] or whatever and then if they want to talk about it then they can, and then it's up to them if they want to disclose what they discussed.

Appendix O

Letter of Approval from the Research Sub Committee of the Oxford Doctoral Course in Clinical Psychology

Oxford Health NHS
NHS Foundation Trust

The Oxford Institute of Clinical Psychology Training

UNIVERSITY OF OXFORD

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
Tel: +44(0)1865 226431
Website: www.oxicpt.co.uk

25th May, 2017

Jonathan Codd
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

Dear Jon,

Thank you very much for sending your dissertation proposal to the Research Sub Committee. You now have conditional approval for your dissertation. Full approval is conditional on a satisfactory response to a small number of issues, as follows:

Paper A:

1. Please clarify whether you will include articles from all countries (p5) or only English language/translated ones (p7) or indeed only English language.
2. Your introductory paragraphs do not make it clear whether or not you are referring to studies/the situation for people with intellectual difficulties in the UK or more broadly. Please clarify, as no doubt there will be big cultural differences?
3. Please clarify the original reference for the Double ABCX model.
4. Research questions do need some evidence presented in the Rationale to support them. Please provide some for the quality of the evidence in the papers you will review.

In addition, please note the following when you reach the write up stage (there is no need to reply to these points).

1. You may well wish to edit the level of demographic statistics and detail provided in the introduction – include only that which is relevant and which informs the document. The same applies to the models and theories described – editing would be useful.
2. Quotes need to be accompanied by page numbers.
3. You need to be very careful when using numbers to rate quality of papers – they are not standardised or validated in any way, and this should be clearer.
4. You must put all references in APA format.

Paper B:

1. The title and introduction would benefit from clarification and a rationale for the inclusion criterion, ages 18-29. Twenty nine might be considered quite a way from transition.

Senior Research Tutor and Interim Deputy Programme Director:
Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol.
Tel: (01865) 226375 myra.cooper@hmc.ox.ac.uk

jcodddisscondapp

2. Will both parents of the same adult child be able to take part or not?
3. Homogeneity is noted – would it be advisable to seek greater homogeneity by investigating parents of those whose child has a severe or moderate level of intellectual disability, for example, rather than also including those with a mild level of ability?
4. Your conclusion on p21, immediately above the 'Aim' isn't mentioned before – you need to find a place to make this statement earlier.
5. Your interview schedule needs a bit more work yet – it does not readily tell a story, and many of the questions are leading and/or prescriptive. I have some more detailed feedback on it that may be helpful if you come and find me.

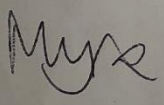
As with Paper A, you must note the following when you reach the write up stage (again, there is no need to reply to these points).

1. There is self-plagiarism from A to B. When you reach the write up stage you must make sure your two papers are sufficiently different, and you must not repeat sentences across the two papers.
2. The reference list for B also needs to be put into APA format
3. You have misspelled some key names in the field (e.g. Glaser, Havighurst)
4. You should make the point, p18, that there is a need not only for more research focussing on transition experiences, but also for work that looks more broadly at transition, not just sexual identity.
5. The language on p21 at the start of the 'Aim' section has a systemic tone, which seems inappropriate in the current context.
6. Please add page numbers to quotes.
7. Please write et al. consistently and appropriately throughout this Paper (and also Paper A).

Finally, it is probably important to say that the document does not always 'flow' very well. In the future it may be useful to try reading the text out loud, noticing where sentences could be framed differently. It applies within sentences and also across sentences and paragraphs.

Please reply in writing, as soon as possible.

Yours sincerely,



Dr Myra Cooper
Chair, Research Sub-Committee

c.c. Olivia Hewitt
Aiysha Malik

Senior Research Tutor and Interim Deputy Programme Director:
Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol.
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Tel: +44(0)1865 226431
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3rd July, 2017

Jonathan Codd
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

Dear Jon,

Thank you very much for your detailed reply to the Research Sub-Committee. In relation to your question about whether or not to collapse the first and second questions on the interview schedule I would pilot it and see how it seems to work out. Do remember that you don't have to stick slavishly to the questions or the order they are written in.

One thing you should change in your introduction to the interview is that it is about transition to adulthood and not transition between services, although no doubt parents will have some things to say about that. Provided you modify that you now have full approval for your dissertation project. We wish you all the very best with your research.

Yours sincerely,

Myra

Dr Myra Cooper
Chair, Research Sub-Committee

c.c. Olivia Hewitt
Aiysha Malik

Senior Research Tutor and Interim Deputy Programme Director:
Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol.
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jcodddissapp

Appendix P

Approval from the Central University Research Ethics Committee

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD
Tel: +44(0)1865 616576 Fax: +44(0)1865 280467
ethics@socsci.ox.ac.uk

1 August 2017

Jonathan Codd
Oxford Institute of Clinical Psychology Training

Dear Jonathan Codd,

Research Ethics Approval (CUREC 1A)
Ref No: R52766/RE001

Title: Having a child with an intellectual disability transition to adulthood: a parental perspective

The above application has been considered on behalf of the Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

Yours sincerely,

Claudia Kozeny-Pelling
Research Ethics Manager and Secretary SSH IDREC

cc: Angela Fox

Appendix Q

Study Consent Form

Oxford Institute of Clinical Psychology Training

ISIS Education Centre

Warneford Hospital

Oxford

OX3 7JX

Jon Codd
Trainee Clinical Psychologist
Oxford telephone number: 01865 226431
Oxford email address: jonathan.codd@hmc.ox.ac.uk

PARTICIPANT CONSENT FORM

Research Ethics Approval (CUREC 1A) Reference Number: R52766/RE001

Having a child with an intellectual disability transition to adulthood: A parental perspective.

Purpose of Study: This research aims to explore parents' experiences of supporting their child who has an intellectual disability transition to adulthood.

Please initial each box

1 I confirm that I have read and understand the information sheet version for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or academic penalty, and that in this event information I have provided will be ☐

destroyed. However, if the information has already been analysed (which is usually up to four weeks following the interview) then my data may be used.

3	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded	☐
9	I understand how audio recordings will be used in research outputs	☐
10	I give permission to be quoted directly in the research publication against my name	☐
11	I agree to take part in the above study.	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

Appendix R

Debriefing Sheet

Having a child with an intellectual disability transition to adulthood:

A parental perspective

Background

The experiences of families with young children with intellectual disability have been widely discussed in the literature but less is known about the experiences among families with transition-age children with intellectual disability. Parental experiences of their child with an intellectual disability transitioning to adulthood has received minimal attention in the UK.

Parents are the most important people in a young person's life and services need to understand parental experiences and adapt to support their welfare and needs. This understanding and support may enable and empower parents to better support and advocate for their child moving forward and in the long term.

Aims

This study takes an open-minded and curious approach to exploring the experiences of parenting a child with an intellectual disability transitioning to adulthood. The main research question is: how do parents, who have a child with an intellectual disability, make sense of their child's transition to adulthood?

Specifically, the focus is on exploring participants' experience of:

1) the positive and difficult/challenging aspects of parenting a person with an intellectual disability around transition.

2) the goals of the person with an intellectual disability

3) the impact within and outside the family.

4) their role in supporting the person with an intellectual disability they parent.

5) the formal and informal support received for the family and for the person with an intellectual disability.

Analysing Data

Analysis of the data begins in the transcribing and reading of the interviews, attempting to draw out themes and discussing them with an experienced supervisor. Analysis begins with close line-by-line analysis of the comments from each participant and is followed by identification of emerging themes and relationships between themes.

Further Information and Support

Talking with people about lived experiences may be therapeutic and for some people it may help them generate new meaning about their experiences. It may also be very difficult to talk about some experiences, which may have been distressing at the time and may cause distress now to think about or talk about.

It was not the intention of this research to cause participants harm or distress by asking questions prompting them to think and talk about their lived experiences of their child who has an intellectual disability transition to adulthood.

Below is a list of services and organisations who offer support and advice:

British Institute of Learning Disabilities (BILD)

Website: http://www.bild.org.uk; **Telephone:** 0121 415 6960;

Email: enquiries@bild.org.uk

Mencap

Website: www.mencap.org.uk; Telephone: 0808 808 1111 (8am - 6pm Monday to Friday); **Email**: helpline@mencap.org.uk

The National Autistic Society

Website: http://www.autism.org.uk/; **Telephone**: +44 (0)20 7833 2299; **Email**: nas@nas.org.uk

Autism Berkshire

Website: http://www.autismberkshire.org.uk/; **Telephone**: 01189 594 594; **Email**: contact@autismberkshire.org.uk

Barnardos

Website: http://www.barnardos.org.uk; Telephone: 0208 550 8822; **Email**: supporterrelations@barnardos.org.uk

Scope

Website: www.scope.org.uk; **Telephone**: 0808 800 3333; **Email**: helpline@scope.org.uk

YoungMinds

Website: http://www.youngminds.org.uk; **Telephone**: 0808 802 5544 (9:30am-4pm Monday to Friday); **Email**: ymenquiries@youngminds.org.uk

Improving Access to Psychological Therapies (IAPT)

Berkshire Talking Therapies: Website: www.talkingtherapies.berkshire.nhs.uk; **Telephone**: 0300 365 2000; **Email**: talkingtherapies@berkshire.nhs.uk

Hampshire iTalk: Website: http://www.italk.org.uk/; **Telephone**: 023 8038 3920**; Email:** info@italk.org.uk

Surrey Mind Matters: Website: http://www.mindmattersnhs.co.uk**; Telephone:** 0300 330 5450; **Email**: mindmatters.surrey@sabp.nhs.uk

Oxford Talking Space Plus: Website: http://talkingspaceplus.org.uk; **Telephone**: 01865 901222**; Email:** talkingspaceplus@nhs.net

Thank you very much for your time and participation in this research.

Jon Codd

Trainee Clinical Psychologist

The Oxford Institute of Clinical Psychology Training, University of Oxford

Appendix S

Ethical Considerations

Consent

All participants provided written informed consent to participate in the study. Participants were provided with detailed information on the research aims, method and how the data will be used. Participants received an information sheet fully briefing them on the topic of discussion, interview procedure and participant rights. They were informed that they could decline any question or terminate the interview if they did not wish to proceed due to the topic of discussion or any other reason.

Participants had the option to withdraw consent on any information disclosed during the process in which case any information that had been provided would have therefore been destroyed. However, they were made aware that if their interview had already been analysed (usually up to four-weeks following the interview) then data would be used. It was not possible to identify participants from the data, as it was anonymised during transcription. In keeping with IPA research, information sheets and consent forms explicitly outlined that participants were consenting to not only data collection but also the outcome and reporting of the research which may include anonymous quotes (Smith et al., 2009).

Confidentiality

All data was stored and handled in accordance with the Data Protection Act (Great Britain, 1998). Pseudonyms were used, and any identifying information was changed or removed to protect participants' confidentiality. Information disclosed about other people, for example relatives and friends, was treated in the same way. Consent of information sharing was discussed with participants, so they understood what may be included in the write up and how details may be modified. Following each interview, data

was transferred immediately from the digital recorder to an encrypted Universal Serial Bus (USB) where transcripts were also stored. Participants were informed before the interviews in the information sheet, consent form and in discussion that confidentiality may be broken if there was any disclosure of risk to them or others. In such a case, the project supervisor was to be liaised with, Oxford Health safeguarding policy and procedures would be followed, and concerns reported to the relevant safeguarding team.

Debriefing

Time for debriefing was offered to participants following interviews. Participants were made aware of their right to withdraw early from research interviews, so they understood that they may choose to terminate the interview if they found the content too distressing. The researcher was a Trainee Clinical Psychologist under supervision and had developed skills in managing and supporting people in emotional distress. Although it was not expected that participants would experience high levels of distress during the interviews, talking about difficult or challenging aspects of parenting a person with an intellectual disability was emotional for some participants, and this was acknowledged with empathy and sensitivity by the researcher. A debriefing sheet was offered to participants providing information and support available such as websites, carers groups and talking therapies.

References

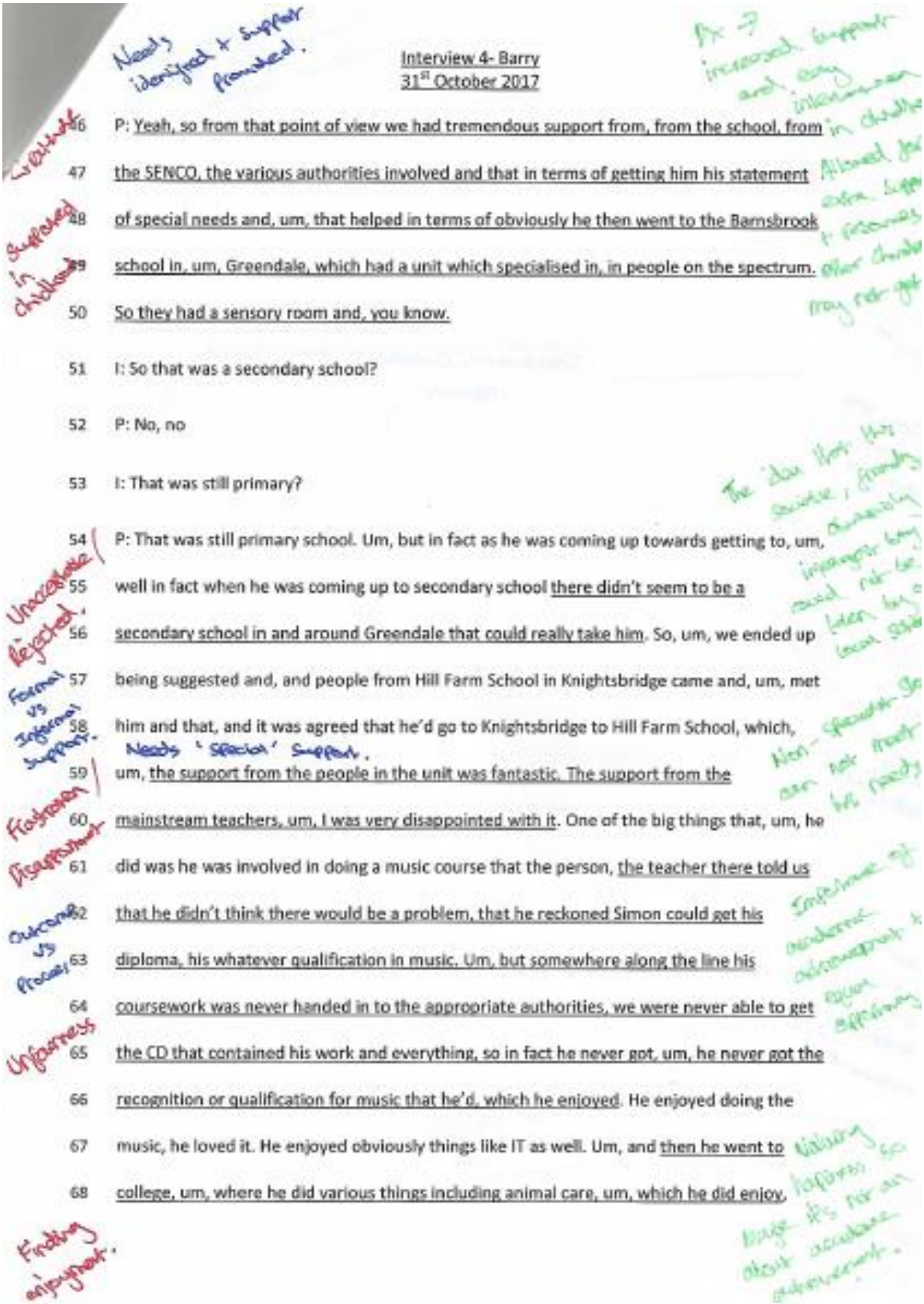
Great Britain. (1998). *Data Protection Act*. London: Stationery Office.

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

Appendix T

The Analysis Process

1) Examples of Annotated Transcripts (Stage 2 from Table 1- Initial noting)



Interview 4- Barry
31st October 2017

P: Yeah, so from that point of view we had tremendous support from, from the school, from the SENCO, the various authorities involved and that in terms of getting him his statement of special needs and, um, that helped in terms of obviously he then went to the Barnsbrook school in, um, Greendale, which had a unit which specialised in, in people on the spectrum. So they had a sensory room and, you know.

I: So that was a secondary school?

P: No, no

I: That was still primary?

P: That was still primary school. Um, but in fact as he was coming up towards getting to, um, well in fact when he was coming up to secondary school there didn't seem to be a secondary school in and around Greendale that could really take him. So, um, we ended up being suggested and, and people from Hill Farm School in Knightsbridge came and, um, met him and that, and it was agreed that he'd go to Knightsbridge to Hill Farm School, which, um, the support from the people in the unit was fantastic. The support from the mainstream teachers, um, I was very disappointed with it. One of the big things that, um, he did was he was involved in doing a music course that the person, the teacher there told us that he didn't think there would be a problem, that he reckoned Simon could get his diploma, his whatever qualification in music. Um, but somewhere along the line his coursework was never handed in to the appropriate authorities, we were never able to get the CD that contained his work and everything, so in fact he never got, um, he never got the recognition or qualification for music that he'd, which he enjoyed. He enjoyed doing the music, he loved it. He enjoyed obviously things like IT as well. Um, and then he went to college, um, where he did various things including animal care, um, which he did enjoy,

Interview 8- Tracy (Connor)
14th November 2017

P: Um, the disabled sports club, swimming club's been, um, a great, um, network for both of us really, and, um, the church com, you know, youth club they've been a good thing as well, a different network there, different activities and, yeah or different, a lot of people from the school go there as well. Um (sighs), what else is there that, oh the youth club, the Friday night youth club I think in Ragley, I think they do a good, they're voluntary service in, in the borough and I think they do an excellent job. They have a, they do a lot of, um, camps and community, community links with the school as well, and try and work with the school and the youth, you know, and the children at the youth club as well, um. I think that's done, that's been really good for Connor, so he did join something called the, the Panthers, the Panthers Club a few years ago he got, um, like a raincoat, you know, a jacket with the Panthers written on it so it was part of that, and that was all about, um, education, relationships and friendships and growing up and so it was like a different forum for him that wasn't a school environment, it was like

I: Yeah but where he could learn and it was safe and

P: yeah youth and youth group that's still fun but still had that side where, you know, about how you behave.

I: And what's it meant for you that there have been all these different sort of groups and services?

P: It's taken a lot of pressure off me because I don't, he doesn't always want to come, I'm his mum, so I'm, I mean I guess Connor sees me, I mean obviously he loves me because he's told me that loads and I know he appreciates me, but I

Fit one full p

Interview 9- Donna (Liam)
21st November 2017

after my dad, it got to the point where I didn't want to be the carer or the nurse for my dad I wanted to be his daughter and I wanted somebody else to take over that care. Um, relationship with, um, my dad and Paul was not great. So Paul has struggled to also be, to, to have been part of that caring. So that put a strain on us. Um, not that we made that, um, we didn't advertise that to Liam but I think he could sense that at times. Um, and then, you know, I'm now looking after a woman that I've got no real feeling or, um, yeah numb, I'm numb to her which sounds dreadful. However, I know that Liam cares for her, is concerned for her and all with his disabilities, the learning disabilities, the autism etc, he has got a very caring side to him and has a concerned side as well. Um, so losing my dad, for Liam, was tough, and still is, still he gets upset about dad, um.

I: And what's that like for you when he does get upset?

P: Um, I think now because I'm dealing with my own emotions I can, I can support him. Um, I've never not encouraged my children to show emotion. So if he says he's feeling sad and he wants to cry then I say well you cry. If that will make you feel better, then cry. Um, sometimes I might say but grandad won't want you crying, he won't want to see you, you know, to see that you're sad. Um, so sometimes ~~we have to do a bit of tough love, ok don't need to do that,~~ we don't need to cry, but what we will do is we'll go and get a balloon and we'll write message and ~~we'll release that~~ for grandad, or, um, he's chosen like a golfing jumper of my dads. Or you can put that on or go to golf or, you know, do something that reminds you of grandad. Um, but we've also made the decision that he will have counselling because, um, I think sometimes he, he does go into,

Patient difficult decisions to make during (re funeral's illness + come)

Mum forced to make some difficult decisions re future care

Shift impact on relationship + family structure

Coping down on individuals but also relation + families.

Parent struggles for child (re importance relationships)

Further progress made for her child in maintaining relationship for him + grandparents

Foster positive view of child

Parent positive view of child

Passing a PUSO to be on top of your own emotions.

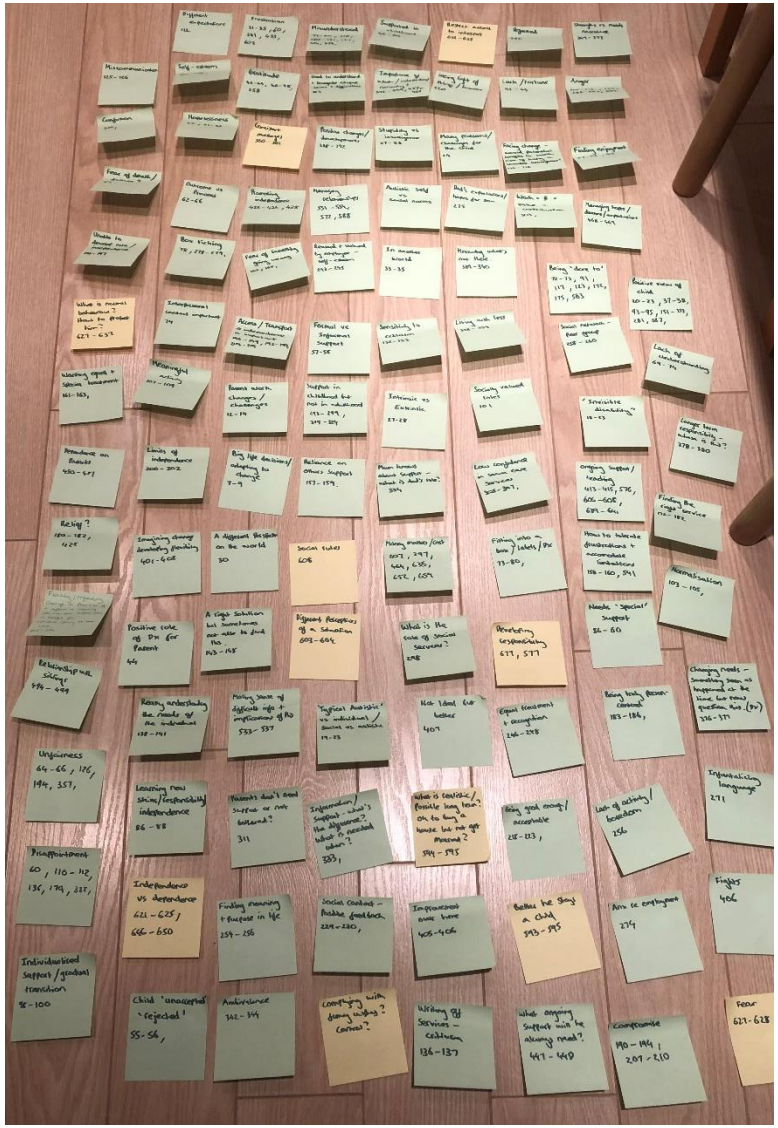
It's important to be in control own emotion to be a good parent.

Parents want/need a number of options / strategies to support child re emotions / grief...

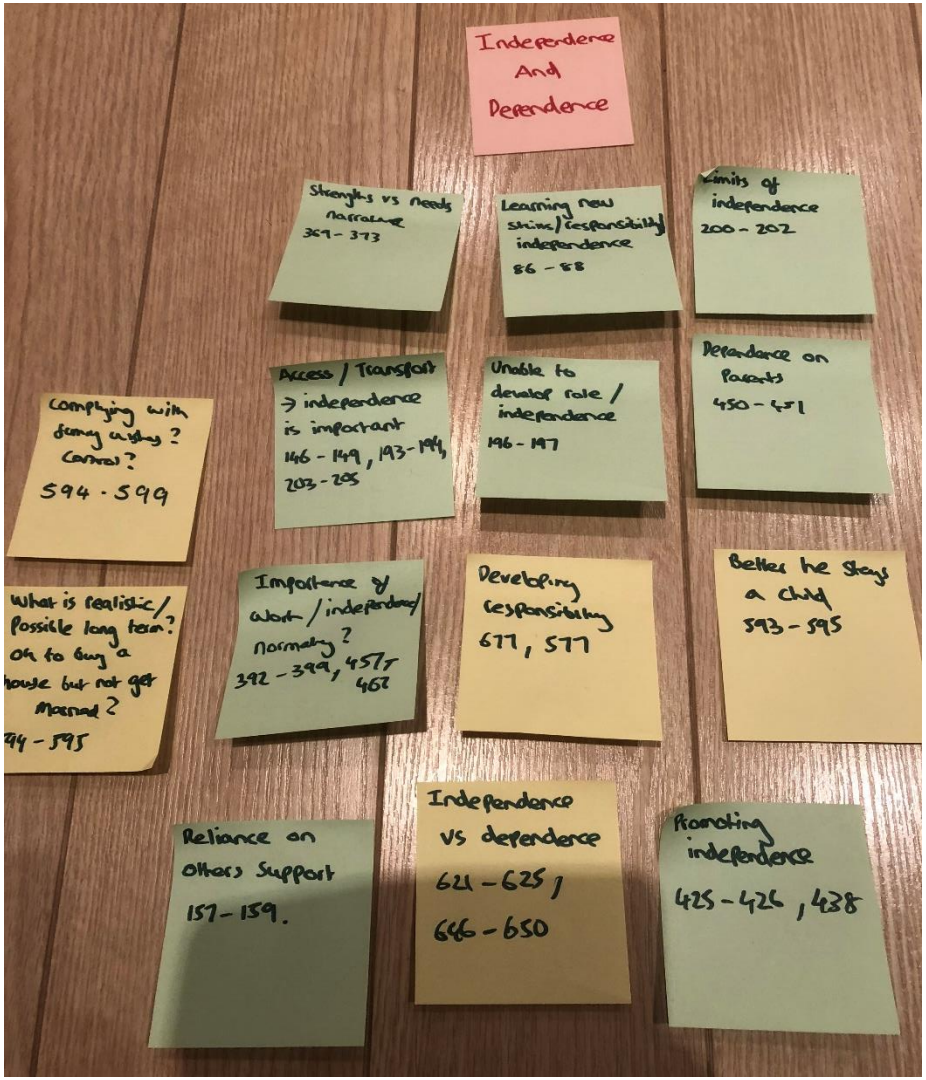
Multiple strategies use for support child with emotions -
(1) Crying
(2) Not Crying
(3) Using a msg symbolic object
(4) Taking / concern

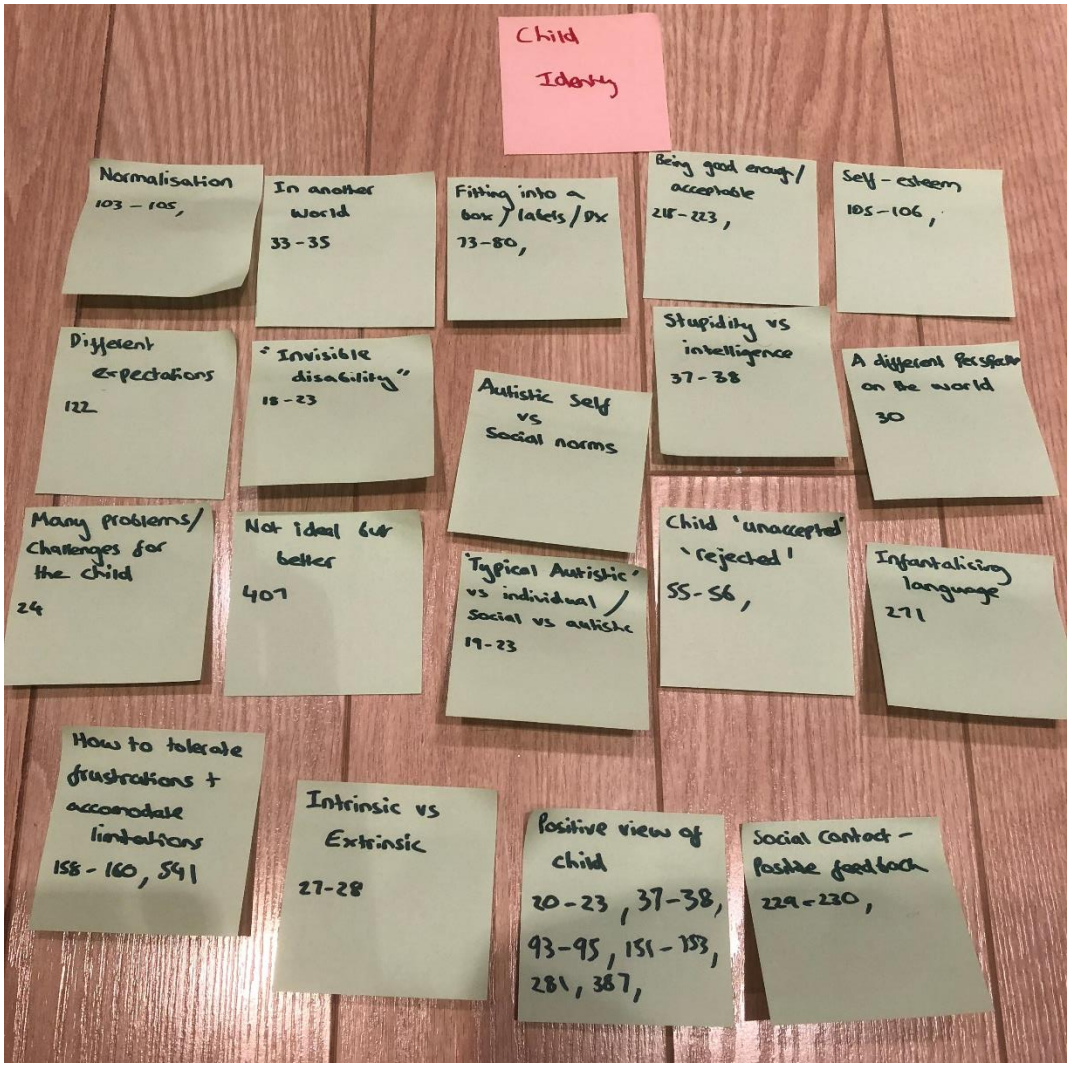
2) Examples of case level summary (Stage 3 and 4 from Table 1- emergent themes and connections between themes)

Emerging themes written out with corresponding line numbers.



Emerging themes then clustered into ‘Master Themes’.





Each interview was typed up into a table to show the master themes and corresponding emerging themes with illustrative quotes. This is an example of two master themes from Interview 8 (Tracey).

Master Theme	Emerging Themes (and line numbers)	Illustrative Quote
Transition and parent-child bond	• Parent complete trust of child (372-373) • Mum feels let down by men in her life- son is only man in her life she can trust (272-291) • Child's affection/care for mum (250-254) • Son showing concern for mum's future (241) • Mum frustration at being ignored by child/not listened to (190-193, 200) • Mother/son bond friendship dynamic now child is an adult (235-247) • Child-adult conversation re relationships (265-266) • Parent-child dynamic and power in the relationship (207-213) • Parent picking and choosing battles with child e.g. home chores (204-207, 209-213) • Things are easier when child is an adult re choices (226-232) • Transition to adult leads to improved communication/relationship with child-adult-adult (234-239)	*"I think it has been easier because I think he feels a bit more in control with his life, and, um, he'll talk to me more now about stuff rather than, I don't know, like he's more communicative about what he wants and how he would like things"*
Child gaining independence/ moving on	• Adulthood leads to motivation for independence and doing more himself leading to less parental support (726-729) • Child's choice/independence re what to answer- freedom of speech (195-196) • Listen to the young person (137-138) • Child seeking independence re leaving home (236-239) • Parent person-centred re will be guided by son as moving out (631-635) • Parent values ideas of independence re moving on and life after mum, (628-630) • Independence re child moving on and leaving home (597-599)	*"What kid leaves home at eighteen and does that? So certainly can't do it for special needs. I said no but I'm not against him going into supported living or moving on, I'm not one of these parents that wants to keep him at home and protect him. I think he does need to move on because I'm not going to be here forever"*

3) Master themes across interviews and illustrative quotes (Step 4 from Table 1)

Interview	Master Themes	Illustrative Quotes
1 Gill and Bethany	Parent Identity of child with LD	*"Bethany is profoundly disabled, cannot do anything for herself, is essentially a baby*"
	Parents' Emotional Experience of transition	*"well you're kind of at your wits ends, you know you think how much more do I have to do to get across what we need to and to get Bethany where we know is the best place for her"*
	Parent Identity	*"I'm pretty sure if Bethany could talk that she would probably say that I want to be a vegetarian because that's the, you know, that's how we are at home"*
	Cost of transition	*"the hours that we've spent researching, preparing, writing, to fight for Bethany, I don't think they've, you know, they know we've been successful but they don't know the cost of that"*
	Transition as a Battle / Fight	*"it had been instigated by this social worker who had reported us. So we had to go through then, um, a whole legal process for nearly a year"*
	Experiences of others during transition	*"there was a transition social worker and, um, she had a niece with, um, cerebral palsy, very similar to Bethany. So she kind of got it. She understood but she left. And I think, and she left because she couldn't do the job anymore because of everything that she had to cope with in the job. We actually felt that she was supporting us."*
	Transition as a process	*"when you reach eighteen things generally fall off the cliff and there's really nothing there"*

Interview	Master Themes	Illustrative Quotes
2 Sharon and Sophie	Things are easier/better in childhood and harder/not so good following transition to adulthood	*"All of these services, as soon as they reach adulthood, do just stop. And there isn't any additional input if you like. You have lots when they're in school and lots of support, you know, whether that's from teaching staff, other professionals You have lots, lots of things up until they turn eighteen, and then it just seems to kind of fall at the wayside. There isn't as much once they turn to adulthood. Even though the need, some of the needs are still there."*
	Parents have to battle and fight	*"And you've got kind of an hour battle to get her to the car or go to the shops"*
	Family context matters	*"I suppose not having any other children it's kind of almost the norm if you like"*
	Parents need help and support	*"So you kind of meet them parents and from other clubs and youth clubs, you, you meet other people and they have different stories and different outlooks and have used different services and things, so, so it's kind of, you get lots of information that way."*
	Parents are understanding/ fair	*"I know what a limited service them kind of things are in the area."*
	Parent emotions and worries	*"And I still get a bit nervous, but that's more me letting go then"*
	Positive experiences of transition/ services	*"I suppose some of the services try not to treat them different, and they do go visits to the pub and stuff like that"*
	Parent-child relationship	*"Wouldn't change her for the world"*
	What parents value/think is important	*"I suppose you need a final decision if you like whether that case is going to be open or whether it's going to be closed. And I don't feel we kind of had that"*
	Child as adult and eternal child	*"that's again because of knowing where she is cognitively…And you wouldn't necessarily let a six-year-old run around without knowing exactly where they are."*

Interview	Master Themes	Illustrative Quotes
3 Debbie and Jess	Transition is difficult	*"she didn't meet the criteria, and they're not obviously going to tell you what the criteria are that she doesn't meet and, um, it's all a bit vague and waffley"*
	What parents want/value	*"what I always wanted was some sort of, um, one to one support that would take her out and so she wasn't so reliant on me."*
	Parent support/ strategies of managing/ coping	*"I've needed support and I go to an [health condition] therapy centre and I've had counselling through them which has actually been beneficial"*
	Family stuff	*"they're all quite different in character, and they're not that close really. They just get on with each other if they see each other but they wouldn't make an effort to go and see each other, so. And they're all fine with Jess but they wouldn't, you know, they're not, it's not bad, there's no arguments or anything like that, it's just they're in their own world."*
	Parent view of child	*"in terms of Down's Syndrome she's doing well and she's got a lot of interests and activities and, yeah, is happy and thriving."*
	Child dependence/ independence	*"I can leave her for a couple of hours in the house. She doesn't go out anywhere independently on her own"*
	Parent role	*"Um, well again to, to, for social engagements you have to facilitate things all the tim*e"
	Luck/ chance/ fortune	*"I was lucky that I happened to go when there was a helpful person there who had a bit of free time and she's not there a few months later"*

Interview	Master Themes	Illustrative Quotes
4 Barry and Simon	Transition working and not working	*"Um, I think basically the, we've not really seen anything about the once he turned eighteen. There was a lot of support obviously in terms of when he was at school, um, he was, um, provided with transport so there was regular interaction with them and they reviewed his statement and all that sort of thing. But once he went to college, um, most of that kind of fell away. Um, we had to pay for his bus fare to college. That wasn't provided for by the borough, and, um, really since then I don't know when we last had anything to do with social services to be* honest"
	Independence and Dependence	*"we're going to get married and have babies, and we'll have three children. No, no, no, this is really not on. And that was quite troubling"*
	Parental feelings – transition is an emotional rollercoaster	*"you have to renew that every year which is ridiculous. The lad doesn't stop suddenly having autism from one year to the next"*
	Child Identity	*"he's not a typical autistic, or he's not what people commonly think of as autistic. He's not the one who sits in the corner and rocks. He's very outgoing, he's very friendly. One might say he's too friendly"*
	What's important to the person	*"I mean he has no one to talk to and obviously it's difficult for him to get out and see friends"*
	Parental Roles	*"so in terms of interacting with any, any organisation, any people, it's really Linda or I that, or the girls even have to, have to do it because he just can't articulate what, what needs to be said or done or whatever. I mean, often even to write a letter for example, he wouldn't know where to start or how to do it. Um, so we still have to do all that for him"*

Interview	Master Themes	Illustrative Quotes
5 Linda and Max	Importance of family and relationships	*"I would die for Max without a moment's hesitation. He is the absolute focus of my world and I love him to bits and I wouldn't swap him for anything"*
	Parent feeling lonely/isolated/ rejected/lack of acceptance/different	*"I don't really talk to anybody about that because, um, it's very difficult to find someone who's in exactly the same position as me"*
	Parent positive experiences of transition	*"we did find adult social care eventually, um, and, um, got in touch with the transition social worker. He was fabulous, he was really helpful, came here several times, took me through the whole process, did the whole assessment thing, um, I produced a document for him on all Max's needs and everything so it made it really easy for him to fill in the form. So we got the budget, yay, no problem at all"*
	Childhood is easier/better and transition/adulthood is unclear/harder/stressful	*"It seems very clearly laid out what the whole landscape looks like for children. But as you move into the adult arena it becomes really foggy, very disjointed it feels like, and it, it, you have to find out a lot of it by yourself it feels like to me, and some things you find out by accident rather than by design, while when you're in children services it's really clear and you know exactly what's happening"*
	Independence/separation from mum	*"Now he's getting older I feel for his independence he needs to have more of a, um, he needs to pull away more, particularly from me."*
	Parent role, identity and coping	*"He's probably still going to need help with going to things like hospital appointments and things, and I don't want a support worker to be going with my son to his hospital appointment. I think that's my job, that's what I should be doing"*
	What parent values and feels is important	*"Most of the time it's ok. Um, there are times when you think (sighs) and I do and that's mainly in my counselling session where I, when all the tears will come and it's just really hard to see everybody else around you and their kids doing things and your child no, so that tends to be where, that is my, that's my main support, which obviously I pay for but, um, that's definitely kept me sane"*

Interview	Master Themes	Illustrative Quotes
6 Ron and Jimmy	Parent Identity	*"I'm not fighting for you, you're fighting for the, the individual with the disability. You're fighting on their behalf and it's as simple and straight forward as that"*
	Child Identity	*"well then from then on he was just treated like as a normal, as a normal person with our family"*
	When things have gone well	*"we felt then that with transition then he should be out a bit more, so we managed to get six hours there, and we were quite happy with that. And obviously from a transport point of view that was fine and dandy it was provided by Ragley Council"*
	Bad experiences of services	*"Um, a minefield if you don't know what you're doing, and if you put the wrong thing down it'll cost you, well it won't cost you it'll cost the individual. Um, and the fact that the, a number of cases that go to appeal and are then are turned over, you know, where they've refused and then turned over, it just shows you that they're not even looking at them properly in the first place"*
	Parent emotional experiences	*"(Sigh) I've, sad that you have to fight for everything"*
	Influences/stories/narratives	*"um, I suppose talking to people, other parents. Um, and to some, some, some of the, um, the, um, mis-haps that have beset other people"*
	The future	*"Um, we're not in any great, um, um, hurry to move him out at this moment in time I don't think he's ready for it"*

Interview	Master Themes	Illustrative Quotes
7 Graham and Matt	Transition to adulthood as being better or worse	*"as he's got older he has become more, almost reflective, in terms of his ability to understand or to, to be able at least to discuss and understand and rationalise the way in which, um, you know, things are happening and what's causing problems"*
	Child Progression and Achievement	*"He had a ball, he really enjoyed Shepherd's Hill, but I don't know that it really did any good for him"*
	Parent view of child	*"we really felt he'd been ripped off so, um, I wondered whether that was because he was vulnerable or not"*
	Impact on the family	*"when he's slowing us up or, you know, when people want to get on and do something and he won't get up or he'll say no, no I don't want to do that"*
	Experience of services	*"there was this guy who was going to come and sort it all out for us, um, and he, I don't, as we speak I still can't remember where he came from, and he came and he was full of excitement, and then we never heard any more from him so I don't know what happened"*
	Disability Identity	*"I think the secretiveness thing, I think some of that is to do with the autistic spectrum stuff, that he doesn't quite process things in a normal way and doesn't always understand"*
	Fighting	"*it has been good in the sense that you can, um, you don't have to be as hands on, you're not fighting fires all the time"*
	Parental Roles and Style	*"it is quite a stress to actually try and keep a family running and to keep everything happening so that it works for everybody, so you don't limit everyone, because obvious, see having, having a child with those sorts of issues as the oldest child doesn't have a knock on effect at all to all the other siblings because it means you can't discipline in a normal way"*
	Knowing, not knowing, knowledge and uncertainty	*"you don't necessarily feel there's full disclosure of information of what's going on"*
	Parental Emotional Experiences	*"wasn't really much point having a strong emotion because it wasn't going to do anything"*

Interview	Master Themes	Illustrative Quotes
8 Tracey and Connor	Parent identity/ roles and responsibilities	*"he'll sit on the bed and he'll talk about stuff and I'm like well I have to because I'm his mum (laughs) and I feel really rotten if I say oh not now I want to go to sleep"*
	PWLD are vulnerable/ need more support/ are complex	*"and I just felt awful, and I spoke to her in the garden because I didn't want Connor to hear"*
	Transition Support	*"I would say, um, social services have been very supportive to us"*
	Transition and parent-child bond	*"I think it has been easier because I think he feels a bit more in control with his life, and, um, he'll talk to me more now about stuff rather than, I don't know, like he's more communicative about what he wants and how he would like things"*
	Transition difficult for parents	*"I kind of agreed with everything they said more or less really, there was only probably a few things where I though oh no that I wasn't sure about, but most, most of it I felt went fairly well"*
	Parent view of child	*"he has grown up, um, to become quite, um, kind boy, um thoughtful, um, quite funny sometimes, um, he, um, has problems processing information and, um, eating has always been a big problem but recent years it's become a lot better"*
	Child gaining independence/ moving on	*"What kid leaves home at eighteen and does that? So certainly can't do it for special needs. I said no but I'm not against him going into supported living or moving on, I'm not one of these parents that wants to keep him at home and protect him. I think he does need to move on because I'm not going to be here forever"*
	Importance of school/ education/ learning/skills/ qualifications	*"this is what I do think, um, I think the school caters more and their focus is more on the younger students, so that's where their area of expertise is. I think the sixth form, um, doesn't maybe get as much focus, I think, that's my feeling, and I wonder whether the col, they should go to college, at, and then have that education"*

Interview	Master Themes	Illustrative Quotes
9 Donna and Liam	Transition is emotional and hard for parents	*"I'm finding it harder to care for my child who is becoming an adult with special needs because when they're smaller you have, I think, more control, more involvement, um, and they are quite open to your, um, suggestions influencing, um, whereas Liam now is starting to get an opinion, other people are involved in his life, um, it's all, you know, they're encouraged to make their own choices, those choices are not always the right choices for us maybe as a family, um, so I'm finding it harder caring for an adult child as opposed to a small child"*
	Parent sacrifices for their child	*"I: I was struck by how you sort of explaining that at points during that transition process that, you know, obviously when you were having to support Liam, all the things that you mentioned earlier that you were doing for Liam but you were also caring for multiple other people at the same time. P: Hence why I'm stepping down at work (laughs) not being a manager anymore"*
	Parents are humans too	*"Um, sometimes I can deal with that and give instruction and think nothing of it and then there's other days where I really struggle with the fact that I am having to give those instructions and they're not being received how I'm saying it"*
	PWLD as a child and an adult	*"So we found it quite endearing listening to him sort of giving advice (laughs). So, so with Liam it's really tough, it's really hard because there's some very immature emotions but there's also some very mature emotions, so."*
	Strategies and Coping	*"he will then phone and I have to talk him through well, you know, we need a loaf of bread, so you choose brown or white. Um, that can cause him quite high anxiety. Facetime is brilliant because he will facetime me and show me the bread etc. Um, his level of making a decision is very very minimal. He does need, um, reassurance or even help, as in what to purchase"*

Interview	Master Themes	Illustrative Quotes
9 (continued) Donna and Liam	Parent Role	*"Yeah, again you, you, you, um, you don't stop being that parent. I know when, you never stop being a parent but the, the caring aspect of it you, you back off a little bit don't you, and you, you give the care and the attention really when that child is asking for it or is struggling, whereas with Liam that, that hasn't stopped, that's continued"*
	Support from others	*"I don't know why once you go over to the adult ADHD, why don't you just get an invite to go in and review the medication then? To me it just doesn't, it's, anyway so, um, so we're just waiting now to try and get this medication for his ADHD because he is, he is really hyper"*
	Family	*"And dad is full time, um, he works as a bricklayer, um , leaves the house about, um, seven o'clock. Luckily he's local at the moment. And his brother also works full time. So our work ethic in this house is quite good. So hopefully Liam will learn from that"*
	Identity of PWLD	*"I know that Liam cares for her, is concerned for her and all with his disabilities, the learning disabilities, the autism etc, he has got a very caring side to him and has a concerned side as well"*

Interview	Master Themes	Illustrative Quotes
10 Tanya and Gaby	Family	*"Gaby with my husband's family, she's, they've been great. Um, so basically for Gaby it's like it was a grandma, my mother in-law, and in that sense everything's fine"*
	Culture	*"in [country]being depressed is not a disability. It's something that you, you, yeah, you're sinking, you get on with it, you get out, no medication needed, and maybe go to the psychologist. You can go to psychologist or Gaby went to the psychologist until she was seventeen, every week, once a week. So the system was totally different. So basically over there you have a support because you go once a week to the psychologist, and you just open everything up, and it helps, I think it helps, but I got used to that"*
	Parent Value- what is important	*"he has another family after. Gaby has younger brother, um, in [another country] but, um, so in that sense she knows, she always knows about everything that's going on. It's not like she doesn't have another side of her family or anything"*
	Surprising, new, unfamiliar	*"it happened all of a sudden I have to deal with now new, new things that I wasn't, since she's the only one with that age that I have. Um, for example I was not prepared for any talk about sex"*
	Parent role/identity	*"I guess I'm learning that I'm more old-fashioned than I thought"*
	Child Identity	*"she's developing more of a personality I guess here. She used to be more, um, how do you say it, dosile? She's doing more yeah ok yeah ok, now she's more no no no no, so yeah it's, um, she's fighting more, she's fighting back more, that's what I'm trying to say"*
	Transition as difficult/ challenging	*"we moved here when she was, um, seventeen, and it was a complete cultural shock. Not for her but for me with the system for people with learning disabilities. It's, um, I don't think they make it that friendly in many ways. Um, at least if you weren't born here and you have to be introduced to the system and get all the processes started like the school, social services, um, the nurse, hospital, everything. And, um, um, obviously I don't, I'm not saying that people involved don't care, it's just the processes they know, it is what it is, and I don't think there's really open mind about when it comes to suggesting things"*
	Coping	***"****I usually try to block the issue and I'm like ok when the time comes and she's like look we talk about this today, I'll deal with it"*

4) Example of development of superordinate and subordinate themes (Step 5 from Table 1- patterns across cases)

Superordinate/ Subordinate Themes	**Master themes from each interview and representative quotes**
How and when parents and child separate	• **What parents want/value**- *"what I always wanted was some sort of, um, one to one support that would take her out and so she wasn't so reliant on me."* (3) • **Parent role, identity and coping-** *"He's probably still going to need help with going to things like hospital appointments and things, and I don't want a support worker to be going with my son to his hospital appointment. I think that's my job, that's what I should be doing" (5)* • **Child gaining independence/ moving on** – *"What kid leaves home at eighteen and does that? So certainly can't do it for special needs. I said no but I'm not against him going into supported living or moving on, I'm not one of these parents that wants to keep him at home and protect him. I think he does need to move on because I'm not going to be here forever"* (8) • **The future** – *"Um, we're not in any great, um, um, hurry to move him out at this moment in time I don't think he's ready for it"* (6) • **Transition is emotional and hard for parents**- *"I'm finding it harder to care for my child who is becoming an adult with special needs because when they're smaller you have, I think, more control, more involvement, um, and they are quite open to your, um, suggestions influencing, um, whereas Liam now is starting to get an opinion, other people are involved in his life, um, it's all, you know, they're encouraged to make their own choices, those choices are not always the right choices for us maybe as a family, um, so I'm finding it harder caring for an adult child as opposed to a small child"* (9) • **Parent view of child** – *"Um, and we really felt he'd been ripped off so, um, I wondered whether that was because he was vulnerable or not"* (7)
Support that is seen as valuable for parents	• **What parent values and feels is important**- *"Most of the time it's ok. Um, there are times when you think (sighs) and I do and that's mainly in my counselling session where I, when all the tears will come and it's just really hard to see everybody else around you and their kids doing things and your child no, so that tends to be where, that is my, that's my main support, which obviously I pay for but, um, that's definitely kept me sane" (5)*

Support that is seen as valuable for parents	• **Parents need help and support**- *"So you kind of meet them parents and from other clubs and youth clubs, you, you meet other people and they have different stories and different outlooks and have used different services and things, so, so it's kind of, you get lots of information that way."* (2) • **Parent support/ strategies of managing/ coping** – *"I've needed support and I go to an [health condition] therapy centre and I've had counselling through them which has actually been beneficial"* (3) • **Importance of school/ education/ learning/skills/ qualifications** – *"this is what I do think, um, I think the school caters more and their focus is more on the younger students, so that's where their area of expertise is. I think the sixth form, um, doesn't maybe get as much focus, I think, that's my feeling, and I wonder whether the col, they should go to college, at, and then have that education"* (8) • **Parent positive experiences of transition**- *"So we did find adult social care eventually, um, and, um, got in touch with the transition social worker. He was fabulous, he was really helpful, came here several times, took me through the whole process, did the whole assessment thing, um, I produced a document for him on all Max's needs and everything so it made it really easy for him to fill in the form. So we got the budget, yay, no problem at all" (5)* • **Family**- *"Gaby with my husband's family, she's, they've been great. Um, so basically for Gaby it's like it was a grandma, my mother in-law, and in that sense everything's fine"* (10) • **Influences/stories/narratives** – *"um, I suppose talking to people, other parents. Um, and to some, some, some of the, um, the, um, mis-haps that have beset other people"* (6) • **Culture**- *"in [country] being depressed is not a disability. It's something that you, you, yeah, you're sinking, you get on with it, you get out, no medication needed, and maybe go to the psychologist. You can go to psychologist or Gaby went to the psychologist until she was seventeen, every week, once a week. So the system was totally different. So basically over there you have a support because you go once a week to the psychologist, and you just open everything up, and it helps, I think it helps, but I got used to that system"* (10) • **Parent feeling lonely/isolated/ rejected/lack of acceptance/different**- *"I don't really talk to anybody about that because, um, it's very difficult to find someone who's in exactly the same position as me" (5)*

5) Example of finalising the arranging of super-ordinate and subordinate themes

(Step 5 from Table 1- patterns across cases)

Themes from analysis with supervisor Themes from analysis with a peer

'Striving for independence'

Parent view of child's ability and potential in the context of having a disability

How the parent views their child- personality and ability

Independence and Dependence

How and when parents and child separate

a) How parents view their child: Ability and disability

"in terms of Down's Syndrome she's doing well and she's got a lot of interests and activities and, yeah, is happy and thriving." (Interview 3)

"she's developing more of a personality I guess here. She used to be more, um, how do you say it, docile? She's doing more yeah ok yeah ok, now she's more no no no no, so yeah it's, um, she's fighting more, she's fighting back more, that's what I'm trying to say" (Interview 10)

"He had a ball, he really enjoyed Shepherd's Hill, but I don't know that it really did any good for him really" (Interview 7)

"Bethany is profoundly disabled, cannot do anything for herself, is essentially a baby" (Interview 1)

"I think it has been easier because I think he feels a bit more in control with his life, and, um, he'll talk to me more now about stuff rather than, I don't know, like he's more communicative about what he wants and how he would like things" (Interview 8)

"Um, and we really felt he'd been ripped off so, um, I wondered whether that was because he was vulnerable or not" (Interview 7)

"that's again because of knowing where she is cognitively…And you wouldn't necessarily let a six-year-old run around without knowing exactly where they are." (Interview 2)

"he's not a typical autistic, or he's not what people commonly think of as autistic. He's not the one who sits in the corner and rocks. He's very outgoing, he's very friendly. One might say he's too friendly" (Interview 4)

b) Letting go and separation: The push and the pull

"And I still get a bit nervous, but that's more me letting go then" (Interview 2)

"Now he's getting older I feel for his independence he needs to have more of a, um, he needs to pull away more, particularly from me." (Interview 5)

"what I always wanted was some sort of, um, one to one support that would take her out and so she wasn't so reliant on me." (Interview 3)

"What kid leaves home at eighteen and does that? So certainly can't do it for special needs. I said no but I'm not against him going into supported living or moving on, I'm not one of these parents that wants to keep him at home and protect him. I think he does need to move on because I'm not going to be here forever" (Interview 8)

"Um, we're not in any great, um, um, hurry to move him out at this moment in time I don't think he's ready for it" (Interview 6)

"we're going to get married and have babies, and we'll have three children. No, no, no, this is really not on. And that was quite troubling" (Interview 4)

Appendix U

Reflective journal

A reflective journal was kept throughout the research process which aimed to develop researcher reflexivity. This encouraged consideration of beliefs, assumptions and preconceptions that may have an influence on the development of the study, the interviews, and the analysis process.

Situating the Researcher

I am a 30-year-old White British male without a disability. My main clinical interests are working with people with intellectual disabilities, Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). Prior to conducting this research, I have had many years of experience supporting people with disabilities, including people with physical disabilities, people with intellectual disabilities, and people with autism. My older brother has Down Syndrome and ASD and my younger sister has Down Syndrome and ADHD. Given my experiences living in my own family I have always been curious about the experiences of people with intellectual disabilities and their families. I previously worked in a sixth form with 16-19-year olds with intellectual disabilities. I have noticed how transition to adulthood may be particularly tricky for people with intellectual disabilities and their families. My younger sister is now 21 years old and her experience of transition, along with many of her friends' and their families' experiences, has furthered my interest in the transition to adulthood for people with disabilities.

One of my assumptions starting this research is that most parents really struggle both emotionally and practically with the demands of their child with an intellectual disability transitioning to adulthood. This may be associated to the view I have that many

parents who have a child with an intellectual disability perceive their sons or daughters as 'eternal children' and therefore understandably protect them from the adult world.

Selecting IPA as the Research Methodology

Given the dearth of research, particularly in the UK, into the experiences of people with intellectual disabilities and their families, there is a strong rationale for a qualitative project. Following a discussion with Olivia (my supervisor), and her previous experiences of using IPA successfully in the field of intellectual disabilities, IPA was deemed the most appropriate method to explore parent's lived experiences. I am both excited and nervous as I had never conducted qualitative research before. I have also not conducted research in the field of intellectual disabilities before. My previous experiences of research at universities and service development work has always been quantitative, and I must admit I feel some apprehension stepping away from my comfort zone. However, the more I read about qualitative methods, and particularly IPA, the more I feel this suits my style, in terms of engaging with people through an interview process and the level of interpretation required during analysis. Despite this, I find myself doubting the usefulness of IPA and many other qualitative approaches. The small sample sizes and reliance of individual interpretations makes me question the research validity and generalisability.

Developing Research Ideas

I feel quite certain that I want to explore the experiences of transition to adulthood for people with intellectual disabilities and their families and carers. I am eager to be as inclusive as possible and want the opportunity to explore multiple perspectives. I want to interview people with intellectual disabilities as well as key family members and potentially other people involved in the person's care such as a teacher or social worker.

Today I discussed the notion of triangulation with my course research tutors as well as a final year trainee on the course. Triangulation is the process of interviewing people separately regarding the same subject matter and then facilitating another interview with all participants together to reflect on similarities and differences from the initial interviews. I feel frustrated because the scope of the project I had in mind is too ambitious for a doctoral thesis. To use IPA and triangulation and do the project justice would require at least double the number of interviews which would require double the amount of transcribing and analysis. There would be a risk of rushing the various stages and therefore not doing the participants or the data justice.

Following another discussion with Olivia, it seems appropriate to focus the research on parental experiences, given the lack of research in this area. Additionally, interviewing parents would enable an understanding about the experience of the transition process regarding a number of people regardless of their level of intellectual disability or other diagnoses. I believe parents are usually the most important people in the lives of people with intellectual disabilities. They often advocate for their child's needs both during childhood and into adulthood. It makes sense to me from a systemic perspective that understanding better the experiences of parents, and therefore improving the amount and quality of support that parents receive, could only have a positive impact on parents and other areas of their system. This includes the person with an intellectual disability as well as relationships in the wider family and with professionals and services. This helps me feel clearer about both the need for research in this area as well as the possible clinical need and implications.

Developing the Interview Schedule

Given that I was unable to use triangulation as a means of including people with intellectual disabilities as participants in this project, I am pleased that I was able to involve some young adults with intellectual disabilities in the development of the interview schedule. The discussions in the groups with the students broadened my thinking about the sorts of questions and topics that might come up when interviewing parents. For example, there was a focus on the future and hopes and expectations such as working, relationships (marriage, sex, social media) and driving. Two of the three groups were very chatty. I found the third group harder to talk to. I think this may be due to level of intellectual disability of some of the students. I think some of the students with ASD had difficulty seeing things from their parents' perspective, possibly due to theory of mind deficits, and difficulty in processing and communicating language and ideas. Perhaps, in hindsight, for these individuals, it may have been helpful to speak individually with them or in smaller focus groups of 2-3 people.

I'm finding it difficult ensuring my questions for the interview schedule remain open and not too leading. As I have read about positive and stressful parent experiences when reading for my Paper A it is very tempting to ask more specific questions. However, specific questions are likely to be based on assumptions and it's important the study remains as open and exploratory as possible. Following further discussion with Olivia, I'm quite happy with my final list of questions which ask very broadly about parent experiences (i.e. of transition generally, being in the family, services for their child, and services for parents). These questions will hopefully allow parents to consider some of the issues that the students raised in the discussion groups.

Bracketing Interview Prior to Data Collection

I completed a bracketing interview today with four peers at university who are also using IPA for their projects (see Appendix N). Overall the bracketing process helped me re-consider and focus my attention on some issues such as what inspired me to do this research and what I hope will be gained from doing it. Bracketing also required me to think about other aspects of the research that I hadn't given as much consideration to such as how the interviews may affect me and how I will manage some of my own emotions regarding the subject matter both during and after interviews. In particular, bracketing, as well as supervision, has helped me to consider which parents may or may not be appropriate participants. There is an element of uncertainty about interviewing parents who I already know or who I know through family or friends, and how I manage these 'dual relationships' during and after the interview process. I left the bracketing interview wondering if I had made the right decisions regarding my sampling.

Pilot Interviews

I'm pleased with how the two pilot interviews went and perhaps surprised at how quickly an hour passed. On the one hand I feel the questions allowed for a deep level of conversation. On the other hand, I wonder if I could have explored some of the topics for longer. However, this would either be at the expense of asking other questions on the schedule or of the interview lasting a lot longer than one hour.

Gill's Interview

Going into the first interview I felt a bit nervous about remembering everything (consent form, demographic questionnaire, debrief, payment), ensuring that the interview flowed naturally and covered a range of topics, and trying not to ask leading questions. I noticed I felt frustrated and annoyed during the interview when hearing about Gill's

difficult experiences with her daughter's transition, particularly the invasiveness of social care questioning the families practice with regards to safety and quality of life, and going through court processes regarding deprivation of liberties, adding extra stress to what was already a difficult time. The lack of support from family and friends also struck me and made me feel thankful of support my parents and siblings have. I was taken aback by the resilience shown by Gill and being able to channel her energies into creating a charity and support network to support other families including children with disabilities. Gill asked questions about my training, plans for my future career and interest in working with people with intellectual disabilities, which opened a conversation about my family background which I felt happy to disclose and share. It felt like this strengthened the rapport as we then had something in common as family members of people with disabilities. However, I also wondered if she made any assumptions and therefore didn't describe or explain certain things during the interview.

Sharon's Interview

On the back of the first, going into the second interview I felt more prepared with questions and prompts in my head rather than relying on the interview schedule. As I know Sharon and her daughter through family connections, I made it clear before we started for Sharon to explain some things for the purpose of the research even if she knows I already know (e.g. some information about family context and school). Sharon's daughter was in the room during the interview, which I wasn't necessarily expecting. I checked before we began if this was ok and that it was not going to prevent Sharon from talking about her experiences and her feelings. I found it hard at times not to be leading as there were some things I knew about Sharon and her daughter but waited for things to come out naturally in the interview. I also found it hard to stay neutral as I agreed with

most of the things Sharon said and I wanted to normalise these feelings and experiences based on my own knowledge and experiences. I was struck by the sense of a sudden reduction of services and opportunities when Sharon's daughter reached adulthood, and also a sense of potential isolation for families similar to Sharon's.

Debbie's Interview

This felt like a different type of interview. Debbie seemed to have little faith in intellectual disability services and was keener to steer her daughter away from intellectual disability groups etc and really encouraged her daughter to do well and achieve in activities such as swimming competitions and playing the violin. I was quite shocked by this and it felt quite a contrast to the previous two interviews and from my own values and experiences. It made me question a bit whether how my family support and raise my sister is somehow wrong or not promoting her to be as independent as she could be. I didn't feel angry but perhaps more surprised or even slightly jealous. However, I also noticed a lot of similarities to the other interviews in terms of Debbie's daughter's schooling experiences and relationships. It seems that after only three interviews many similar themes have emerged and yet I also recognise how different all three children and their families are.

Barry's Interview

I noticed some similarities between this interview and the previous one with regards to parents encouraging/supporting their young adult to be as independent as possible. Additionally, Barry was not happy with his experiences of services and therefore not willing to use or rely on services at all which feels like a shame. At times Barry went off on a tangent a bit and I felt slightly irritated by this knowing that I would be spending time transcribing information that isn't all relevant. I perhaps also feel

irritation towards myself for not politely interrupting and steering the interview back on track. Barry was good at describing situations and events but was less good at saying how he felt or what the meaning was for him as a parent. I felt at a loss at times of what other questions to ask to try and elicit this kind of information. However, I was also pleased to have interviewed a father as I was keen from the outset to ensure a few fathers were included in the sample.

Linda's Interview

This felt like the easiest interview so far as Linda was very clear about the transition process for her son and the services that were and weren't involved. She was also very psychologically minded and willing to disclose the emotional impact and meaning of events on her personally as a parent. I was quite relieved about this. It may have helped that Linda had engaged with counselling so is perhaps more self-aware and used to reflecting and discussing some of these topics and issues. I felt myself very drawn to wanting to help and mentioned some other local services and groups that I know about. Coincidentally, Linda also knows some families that I know so it felt like we had something in common. Linda seemed very interested in the research and reading it once it's completed which I felt quite flattered and proud about. I guess it just reminded me of the bigger picture and the possible implications for the findings of this study. I found myself agreeing with a lot of what Linda said during the interview. Perhaps it also helped knowing some of the services she was talking about such as the school her son goes to as well as child and adult mental health services.

Ron's Interview

Ron put me on edge a little bit to begin with. He seemed a bit anxious prior to the interview asking lots of questions about confidentiality and how the data would be used,

using direct quotes etc. However, once the interview was underway we both seemed to relax, and Ron was quite a story teller. It felt like he wanted to give examples and stories for everything which I noticed myself feeling frustrated at times. I started to worry that the interview was going to end up going on for two hours. I wonder following the interview if this distracted me from actively listening to Ron and following up with further prompts to some of his stories and reflections. It was interesting and refreshing to hear a parent talk about transition as quite a smooth process which surprised me a bit and I tried to remain open and curious. Inevitably some challenges and difficulties came up which we also explored. It was interesting to interview an adoptive parent, and I could relate to some of this being in a family where my parents also adopted children with Down Syndrome.

Graham's Interview

Graham and his wife both have quite academic backgrounds which made me question my competence as a researcher. Once again, I experienced more questioning about the study prior to the interview which put me a bit on edge and I felt a bit challenged about what I was doing and why. However, similar to before, once the interview started it seemed to flow well and Graham seemed quite open about his experiences as a father. I guess this has taught me not to worry too much about the pre-interview dialogue. It was interesting hearing Graham's experience of being a parent in a family where the oldest child has an intellectual disability and how transition was different compared to his other three children. I resonated with Graham's comments regarding the impact this had on his other children. It made me reflect about the impact on siblings more generally and my own experience of being in a family where the oldest child has an intellectual disability and how things would have been different if my

siblings did not have intellectual disabilities. I was also interested in the positive narratives Graham had about his son. Graham seemed very proud that his son had managed to get through school, complete his GCSE's, go to college and now hold down a job. Although Graham spoke about his son being diagnosed with ASD and a moderate intellectual disability, I did find myself querying during the interview if his son really does have an intellectual disability and whether he could have been mis-diagnosed. This combined with answers from the LDSQ made me question the validity of the interview, although I tried to put this to one side during the interview so I could focus on what Graham was saying and respond curiously. I found this tough at times though with all the other thoughts and questions buzzing about in my head.

Tracey's Interview

This interview felt like it flowed quite well. I assume it felt this way because Tracey's son is a friend of my younger sister and Tracey appeared very trusting and relaxed about being interviewed as part of the research. The interview elicited a number of interesting discussions which were tricky to navigate at times such as sex, relationships, sexual abuse, and being a single mum. I felt quite emotional and incredibly respectful of Tracey hearing her story and journey, and how she and her son have managed together through his transition. However, I was shocked how Tracey still wonders if she's a 'bad mum' because to me it appears that she does absolutely everything she can for her son. I thought about how hard it must be when there are no siblings and little support from other family. It highlighted for me the importance of social groups and support networks, both for parents and young people with intellectual disabilities.

Donna's Interview

This interview surprised me as social care was not mentioned, probably due to the lack of it. Most of the interview focused around family dynamics and what it was like for Donna to be a parent of a young man with an intellectual disability, ASD and ADHD though transition, when there is so much else going on in the family. This made me think about parents being in the sandwich generation having to cope with illness, disability, loss, and death in the generation above them whilst coping with teenagers and young adults in the generation below. In this family, Donna also has an older son, so she was able to reflect on the differences between parenting him and parenting her younger son who requires a lot more attention and support, and how that feels. There was also some discussion about CAMHS and adult mental health services and I was shocked at some of the experiences she and her son had, including the lack of consistency and one professional swearing during appointments. This also felt a bit tricky for me to hear because I had worked in the same CAMHS service on a previous placement so was aware of the team and some of the individuals that Donna mentioned. I felt disappointed to hear these things being said about a team I had respected and enjoyed working with.

Tanya's Interview

This interview felt different to the others in that the focus was more about family dynamics, relationships and culture as opposed to focussing on services. I felt uncomfortable at several points during the interview as I didn't particularly agree with some of Tanya's views regarding her daughter's rights and her future. However, I did empathise with Tanya and her position, because she was familiar with laws, culture and beliefs in one country and has had to adapt and adjust to a new country. There were also additional worries that I hadn't considered such as the impact of Brexit and financial

support for adults with intellectual disabilities who haven't lived in the UK for longer than three years.

Completion of Interviews

I feel both a sense of relief and sadness to have finished conducting the interviews. I have enjoyed listening to parents and hearing their stories and experiences, both in the ways they have resonated with my own experiences and understanding of transition, and in how they have challenged and prompted me to re-consider some of my ideas and beliefs. At the same time, I am now also feeling overwhelmed from the amount of information in all the interviews and how I can possibly do the participants and data justice and make some kind of sense of it all.

Transcribing

In many ways I would be very happy never to have to transcribe an interview again. It just takes forever. Or maybe it's just made me reflect how slow I am at typing and how stubborn I am not to pay someone else to transcribe my interviews. Having said that, I have found the process of transcribing and listening back multiple times to what parents have said very interesting. It has certainly helped me to think about what was said from a different perspective and without the pressure of engaging the parent and thinking about possible prompts and further questions. I only wish I had started jotting down ideas and notes during this stage rather than leaving the analysis until later.

I found it quite difficult transcribing and listening again to Tracey's interview and the sexual abuse her son experienced. It reminded me how vulnerable people with intellectual disabilities are to being abused and I started to worry about whether either of my siblings have suffered abuse. This interview also prompted me to think more about some of the moral and ethical issues around people with intellectual disabilities regarding

sexual relationships and human rights, and the balance of parents wanting to keep their children safe and avoid unintended consequences (e.g. pregnancy).

Developing Emerging Themes and Master Themes in Individual Transcripts

I have attempted to write down all themes from Interview 1 onto post-it notes and the line numbers for when each theme occurs. I then clustered themes into categories or 'master themes'. As I was writing themes down I was surprised and saddened by the number of re-occurrences of themes particularly related to negative emotions/experiences/costs for this parent. At first the process felt really uncertain but eventually it became clear that there were several categories that the majority of themes could fall into. There were some themes that could have fallen into more than one category and there were other themes that didn't obviously fit into any category, and it was sometimes tricky to decide which category, if any, a theme should go.

Sessions with an IPA Expert

Some trainees using IPA met with Michael Larkin for two sessions to discuss analysis. I took away some key learning points from these sessions. Firstly, the importance of themes standing alone and making sense (e.g. 'transition is a difficult and emotional time for parents' rather than 'parent emotions' or 'parent identity').

Secondly, Michael emphasised the importance of considering the objects of concern for each parent as well as the meanings derived from them. I feel that I have incorporated this more as my analysis has developed. One helpful change I have made is reading through each interview and writing down the key points of interest/messages/objects of concern and then going through doing the line-by-line analysis. At the end of the line-by-line analysis I go back to the key points of interest and make sure each point is somehow reflected in the analysis which inevitably it almost

always is. Sometimes it is tricky deciding to pursue with one idea/theme at the possible expense of another. However, I was able to do this in having faith in the data/process that over ten interviews genuine themes would emerge one way or another.

Thirdly, Michael talked a bit about themes being in agreement, in conflict, reciprocal, more conceptual, or narrative. For example, some parents spoke of transition being a difficult time but for very different reasons such as lack of support from services or because of other difficult life events like another family member being unwell.

Finally, Michael encouraged us to consider psychological concepts/theories for the different themes that have emerged at case level interviews. This prompted me to consider theories of carer stress and lifespan models which have underpinned the background sections to both my papers.

Meeting with Supervisor to Discuss Analysis of First Interview

Today Olivia and I met to discuss the themes that emerged from the first interview. Several themes arose from our conversation: 1) The idea of luck/fortune or unlucky/unfortunate (e.g. having a child with an intellectual disability and what this means); 2) Ideas across different cultures and what this may mean for people and the literature that looks at this; 3) Government policies and processes around what is set up for transition to adulthood and what's actually happening at ground level- there seems to be a disparity and we're wondering what that is about?; 4) Information that parents provide in the interview about diagnosis/childhood is helpful to contextualise the transition which is discussed and can be included in the analysis; 5) Impact on siblings- whether to consider this as a separate emerging theme or whether this comes under a broader umbrella of 'family experiences of transition'. It has been very helpful to discuss an interview in detail with Olivia. It has both clarified and challenged some of my ideas

about the meaning this participant has made of her experiences. Part of me wished I had the opportunity to meet with Olivia to discuss every theme for every interview, but I have to trust my own judgement and the IPA process.

Meeting with Supervisor to Discuss Themes Across Three Analysed Interviews

Today Olivia and I met again to discuss the emerging themes from the first three analysed interviews. One interesting observation is the reoccurrence of some themes (e.g. money/cost, luck/fortune, parent emotions, identity, battles/fights). Another interesting point is that for the two dad's I had more interpreting to do when it came to emotional experiences (e.g. banging the table was an indication of frustration/anger) whereas the one mother described her emotional experiences regularly and in detail. I wondered if this research warrants analysing transcripts for mothers and fathers separately and whether father's experiences may somehow get lost in the voices of mothers who were a majority of the sample.

Reflections on Analysis of Interview Transcripts

I have experimented with different methods of analysing interviews including writing all emerging themes and line numbers onto post-it notes and then arranging them into clusters and developing master themes. I have also used a similar process by just typing out themes into a list on Word and then cutting and pasting themes into lists. I found as I was analysing each interview that it became important to be more specific regarding the emerging themes. So rather than just writing 'parent frustration' I would write 'parent frustration regarding meeting with social worker' or 'parent frustration regarding lack of work experience opportunities for young people with intellectual disabilities'. This helped later on when considering points of interest/subject matter-

deciding whether the subject matter was actually the parent talking about emotional difficulties or whether the subject matter was an emotion about X or Y.

Meeting with Supervisor to Discuss Analysis Across Interviews

I met with Olivia today to start analysing themes across nine of the interviews that I have analysed. I have cut out themes for each interview along with a quote that I felt was a good representation of the theme. Olivia and I then organised the themes into clusters. It felt very messy/slap-dash a times, and I sometimes felt it important to go back to the 'emerging themes' for each theme and think about other quotes from the parents before making a decision which cluster a theme could belong. Also, there felt a need to try and give each theme a place. Eventually we did although this seemed to occur naturally and didn't feel too forced. This process will be repeated to see what other interpretations there may be of the data and how similar or different these are to one another. Olivia and I also discussed how time-consuming IPA can be and how to know when to stop analysing.

Meeting with a Colleague to Discuss Analysis Across Interviews

Today I met with Karla, a colleague and friend who is a qualified clinical psychologist with experience of using IPA. We went through the process again of arranging themes across all ten interviews. Once again this felt like chaos to begin with, but it was a helpful process to go through each theme and discuss our interpretations of meanings and where each theme could go. Often it felt like there were multiple clusters a particular theme could go, and we went with the cluster that we felt was most appropriate/poignant, sometimes having to back to the table of themes to look at the initial emerging themes that represented each over-arching theme to help us make a decision. I was aware of trying not to influence Karla because of my preconceived

ideas/clusters having gone through this process already with Olivia. I was struck how similar the over-arching themes were between the two analyses, something I hope to explore further with Olivia

Writing Up

I am thankful for Michael's advice which was to have a word limit for the entire results section and then divide this up between the number of super-ordinate and subordinate themes. I am also thankful for my table of illustrative quotes across all participants. I find it hard to choose between quotes and remove some quotes because I feel each time I do this I am losing something important that someone has said. I have learnt how to select parts of quotes or allow what one parent has said more succinctly to perhaps represent what several different parents have alluded to. I am surprised at how quick writing the results section was in comparison to how long the whole analysis process has taken.

Credibility Checks

As well as Olivia, Karla and Susie (research tutor), Amy and Tammy (trainees also using IPA) have also discussed and commented on various stages of the analysis. This has been really helpful to gain other perspectives regarding which themes hang well together; ideas for moving some themes around; querying what some of the themes (e.g. 'family') actually mean; and considering if some themes need re-naming or incorporating into other themes. This also reminded me that, following the sessions with Michael Larkin, perhaps emotional experiences should not be a standalone theme but could be part of something else (e.g. difficult experiences during transition- which could also include experiences of services, parent role, family issues etc).

Appendix V

Additional Parent and Child Demographic Information

Family Contexts

All children were biological children except for Jimmy, who was adopted. Three of the children (Sophie, Max and Connor) were an only child; four of the children (Jess, Simon, Jimmy and Liam) were the youngest child in their families; and three children (Bethany, Matt and Gaby) were the eldest child in their families.

Ethnicity

Nine parents reported themselves and their child as White British and one parent reported themselves and their child as White Mediterranean.

Religion

Eight parents reported themselves and their child as Christian, with two parents reporting themselves as atheists, one of which reported their child as an atheist and one parent did not record the religion of their child.

Sexual Orientation and Relationship Status

All parents reported themselves as heterosexual, with six parents married, three divorced, and one single. All parents reported their children as single, with eight parents reporting their child's sexual orientation as heterosexual and two as unknown.